

# Washington Integrated Services Enhancement (WISE) For Children with Special Health Care Needs Grant

Recommendation Report  
July 2005





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Developed by the Children with Special Health Care Needs Program and WISE  
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# I. Executive Summary

## A. Purpose of the WISE Grant Recommendations Report for 2001-2005

The WISE Grant Recommendations Report provides an accounting of activities and findings related to the WISE Grant and recommendations for integrating services for children with special needs in Washington State. This report will:

- Serve as a comprehensive reference document for developing state/community work plans and identifying champions;
- Serve as a menu for independent efforts in strategic planning and priority setting;
- Provide documentation of the WISE Grant findings and recommendations.

A variety of audiences can use this report including WISE Grant participants, state agency leaders, policy makers, family leaders, community agencies and local community coalitions.

## B. The Changing Climate

*“Applying for services for our daughter is labor intensive. I have a file drawer full of applications to various agencies and they all ask for much of the same information. We have completed multiple applications for state services, all asking the same basic questions.”* – Bob Kaczka, Parent

Children with special health care needs are defined as those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally. These children and their families face a complex system of care. With multiple agencies providing a variety of services to children, families often find services difficult to locate, use, and navigate. In June 2001, the Washington State Department of Health Children with Special Health Care Needs Program received a grant (WISE – Washington Integrated Services Enhancement) from the federal Department of Health and Human Services to study and make recommendations to improve systems of care for children with special health care needs and their families.

From the beginning of this grant, parents and professionals worked together to develop a vision for families in Washington State. They were asked to dream about a system that would work FOR THEM. They envisioned one comprehensive, integrated system that meets the unique and evolving challenges of children with special needs and their families in Washington State.

That vision has remained constant. The recommendations contained in this document reflect the needs of families. It is time now for agency leaders to take the next step in supporting these families and pave the way for systemic changes within Washington State.

## C. Four Integration Goals

The WISE Grant focused on four goals to improve services for children with special health care needs:

- Common Application
- Care Coordination
- Integrated Data
- Blended Funding

These goals provided the framework for all WISE Grant activities. They served as the foundation for all committee work, systems research, and family perspectives. This report presents findings related to these goals and recommendations for next steps.

## D. Recommendations

### Service Integration

**Issue:** Families of children with special health care needs face a complex system of care. With multiple agencies providing a variety of services to children, families often find services difficult to locate, use and navigate.

**Recommendation 1:** Designate one lead entity to direct integration of services across agencies for children with special health care needs.

**Recommendation 2:** Involve parents and family leadership in all aspects of state program planning related to children with special health care needs.

### Common Application

**Issue:** Families often must complete numerous enrollment forms and provide information about their child repeatedly to various individuals in multiple agencies and programs. Families have often expressed dismay and frustration with this redundant, emotionally and physically exhausting process. Increasing the ease of enrollment would be beneficial to families and would reduce duplicative efforts in state systems.

**Recommendation 1:** Develop a system for a common application process for families and professionals to access local and state resources for children with special health care needs.

## Care Coordination

**Issue:** The system of care for children with special health care needs is complex, making it difficult for families to identify payment sources, locate family support, and access needed services. Families need a primary point of contact for care coordination that can most adequately meet the needs of the child and family.

**Recommendation 1:** Create a common care coordination vision and a set of goals for agencies and families to use in providing care coordination for children with special health care needs.

**Recommendation 2:** Promote the concept of a primary care coordinator to help facilitate services, across agencies, for children with special health care needs and their families.

## Blended Funding

**Issue:** Currently, a variety of state and federal funding sources exist. Funding of services for children with special health care needs is complex, compounded by categorical funding streams, multi-agency responsibility for service provision, lack of health insurance, and difficulties in billing for services provided.

**Recommendation 1:** State agencies will combine funds whenever possible for activities, such as cross agency trainings, that will improve services for children with special health care needs.

**Recommendation 2:** Continue to research the benefits of blending funds for children with special health care needs across state agencies.

## Integrated Data

**Issue:** Many of the elements that can increase the integration of services for children with special health care needs, including common enrollment, continuity in care coordination, and even maximization of funding could be driven by integrated data systems. If appropriately designed, an integrated data system could meet the needs of all agencies that use it to promote the above mentioned integration enhancements and improve efficiencies in service delivery, resource allocation, and communication.

**Recommendation 1:** State agencies will commit to data integration for children with special health care needs as a long-term goal.

**Recommendation 2:** State agencies will link data bases for children with special health care needs internally in order to establish quality improvement strategies and understand the needs of the population.



## II. Introduction

Katie Kaczka, who was diagnosed at eight months with profound bilateral sensory neural hearing loss, is a lively seven year old who is mainstreamed in her first grade class. “We have a happy, active, and well adjusted child,” says father, Bob Kaczka. “When we got Katie’s diagnosis seven years ago we thought that she had lost her future and we were devastated. As we began the process of finding help, we had no idea that the road to coordinating services for her would be so confusing, difficult, and frustrating.”

Bob, who has served as a parent consultant on the WISE Grant Steering Committee for the past four years, has first-hand experience dealing with the confusing maze of paperwork and service delivery for children with special needs that exists in Washington State. He reports that Katie’s paper work now completely fills a filing cabinet and knows that he is among the lucky few who have the time to become the full-time care coordinator for their child. “We did not have a lack of resources,” he says, “but we were mired in paperwork, often completing multiple applications that asked the exact same questions. The agencies did not coordinate or communicate with each other. At the time that we needed to emotionally deal with this tragedy and spend time as a family, I was most often at my desk feeling overwhelmed with the paperwork.” Bob participated on the WISE Grant project because he wanted to help pave the way for changes in state systems to make this journey easier for other parents. “I know that we are among the lucky few who found a way to navigate this system,” says Bob. “I want to help the many parents I have met, who have become absolutely lost in the stack of paperwork and never found their way out.”

Bob’s story is representative of many Washington State families. According to the National Survey of Children with Special Health Care Needs,<sup>1</sup> approximately 211,000 children (13.7%) in Washington State ages 17 and younger have special health care needs. These families face a complex system of care. With multiple agencies providing a variety of services to children, families often find services difficult to locate, use, and navigate. In June 2001, the Washington State Department of Health Children with Special Health Care Needs Program received a four year grant, (\$223,000.00 per year), from the federal Department of Health and Human Services to study and make recommendations to improve systems of care for children with special health care needs (birth to eight years) and their families.

At the beginning of this grant, parents and professionals worked together to develop a vision for families in Washington State. They were asked to dream about a system that would work FOR THEM. They envisioned one comprehensive, integrated

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1. The National Survey of CSHCN is a nationwide household survey conducted by the federal Maternal and Child Health Bureau and the National Center for Health statistics from 2000 – 2002 to assess the prevalence and impact of special health care needs among children in all 50 states and the District of Columbia. The data can be accessed at <http://www.cdc.gov/nchs/slats.htm>

system that meets the unique and evolving challenges of children with special needs and their families in Washington State.

That vision has remained constant. Family leaders throughout the state have been involved in the WISE Grant process. These recommendations reflect their needs. It is now time for agency leaders to take the next step in supporting these families and pave the way for systemic changes within Washington State.

## **A. Purpose of the WISE Grant Recommendations Report for 2001-2005**

The WISE Grant Recommendations Report provides an accounting of activities and findings related to the WISE Grant and recommendations for integrating services for children with special needs in Washington State. This report will:

- Serve as a comprehensive reference document for developing state/community work plans and identifying champions;
- Serve as a menu for independent efforts in strategic planning and priority setting;
- Provide documentation of the WISE Grant findings and recommendations.

A variety of audiences can utilize this report including: WISE Grant participants, state agency leaders, policy makers, family leaders, community agencies and local community coalitions.

## **B. Background**

Children with special health care needs are defined as those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type or amount beyond that required by children generally.<sup>2</sup> These children may have a wide variety of conditions and illnesses, from birth defects requiring permanent feeding tubes, to disorders that hinder their physical and mental development. These children often require services from a variety of systems, including primary health care, medical specialists, schools, child care, early intervention services, therapies, mental health, public health and family support. Washington State data from the 2001 National Survey of CSHCN showed that prescription medications, dental care, and routine medical care were the services most needed. Of these children, 52% needed to see a specialist, and about 28% needed mental health care in the 12 months prior to the survey.

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2. McPherson et al, 1998 "A new definition of children with special health care needs." Pediatrics 102:137-140



The type of services needed and the duration of a child's participation in any program or service varies, depending on the needs of the child. Transition between programs and among providers adds complexity for families trying to navigate the service systems. According to the National Survey of CSHCN, about 32% of Washington's children with special needs in this age group were enrolled in special education programs. In Washington State, public programs providing services for these children and their families are spread across multiple agencies. Each agency has individual state and federal operating guidelines, reporting requirements, cultures and mandates regarding their service delivery responsibilities. This has resulted in a complex system of care that is difficult for families to navigate and contributes to duplication of efforts and inefficiency in resource allocation across state agencies. The lack of integration of services for children with special needs is recognized as a problem both nationally and in Washington State. The 1999 and 2004 Maternal and Child Health five year needs assessments, conducted by the Department of Health Office of Maternal and Child Health identified care coordination for children with special needs as a priority need.

Currently, five state agencies (Department of Health, Department of Social and Health Services, Office of the Superintendent of Public Instruction, Department of Community Trade and Economic Development, Services for the Blind) partner in an interagency agreement to promote and provide services to children with special needs in Washington State. Children can receive services from a combination of the above agencies in addition to receiving services from multiple community providers. Receiving services from these agencies involves multiple applications and different eligibility criteria. In addition, each agency compiles data for various reporting requirements in separate data systems that do not interface with one another. Parents and providers have indicated that it would be beneficial to have one common entry portal that is easily accessed and contains reliable information. In response to this confusing system, the WISE grant focused on four goals related to service integration: Care Coordination, Common Application, Integrated Data, and Blended Funding.



### **III. Methods**

Multiple methods were used to study and test the feasibility of implementing the four goals of the WISE Grant. Numerous needs assessments were conducted, input was gathered from the committees, pilot sites, and parent consultants, family leadership and social marketing trainings were implemented, and evaluations were completed.

#### **A. Needs Assessments**

A variety of needs assessments were conducted during the first two years of the grant to identify potential barriers at both the local and state level for implementing each of the goals. Areas of strength were also identified to build upon existing efforts and momentum.

In early 2002, a needs assessment was conducted by a technology consultant to study the feasibility of implementing a web based common application site and linking data about children with special needs across the five state agencies (Department of Health, Department of Social and Health Services, Office of the Superintendent of Public Instruction, Department of Community, Trade, and Economic Development, and Services for the Blind). The consultant reviewed all existing application forms and data fields for the agencies. In addition, key staff from the agencies were interviewed to supplement this review of the data systems. All methods were reviewed by the Common Application Sub Committee and veteran family advisors from the Washington Family to Family Network in order to assure that the research would provide useful information for the grant and families.

By September 2002, an assessment of other states' activities related to the four Wise Grant goals was developed and an inventory of the findings was created. This information was given to the committees and pilot sites to review, and was used to determine if these activities could be implemented in Washington State. Through this methodology, the features of successful efforts and components needed for statewide implementation were identified.

By late 2002, baseline measurements of levels of integration of service were measured in the five pilot sites and committees. The Service Integration Matrix (SIMS) tool was administered and results were sent to the WISE Grant team for review and summation. Pilot sites completed another SIMS tool at the end of the grant to provide comparison on levels of integration at the local level.

In fall 2002, an expert on developing integrated funding strategies for children's services provided a framework for shaping the assessment of funding infrastructure review. Key points from that presentation discussed the need for developing the vision and values, understanding the populations, and understanding interagency collaboration and system point of entry.

In 2004, WISE Grant Steering Committee members determined that a critical step in developing an implementation plan for administering a common application process, integrated data, and care coordination was to identify potential barriers to the proposed integration models. As a result, the CSHCN Program contracted with Children's Hospital and Regional Medical Center (CHRM) to carry out key informant interviews of public agency representatives. The interviews collected qualitative information regarding key informant beliefs about barriers and facilitators to implementing the proposed integration models. Seventeen managers and staff from the following Washington State public agencies were interviewed:

### **Department of Social and Health Services**

Children's Administration  
Division of Developmental Disabilities  
Infant Toddler Early Intervention Program  
Medical Assistance Administration  
Mental Health Division

### **Department of Health**

Children with Special Health Care Needs Program  
Genetics Services Section

### **Office of the Superintendent of Public Instruction**

Early Education  
Health Services  
Special Education

### **Department of Community Trade and Economic Development**

Children's Services

Key Informants were asked about potential barriers and facilitators to implementation of three service integration models developed by WISE committee members. Key informants were asked about policies and procedures, state law and regulations, and agency cultural factors that could influence implementation of the common application model for integrating services for children with special needs. These methods assisted WISE Grant Steering Committee members in developing action steps for implementing integration models.

In addition to studying the barriers and facilitators in the state infrastructure, the grant participants studied the current composition of the population and their unmet needs to help inform their work. Through the CSHCN Road Show, the WISE Grant Steering Committee reviewed results from 1) the National Survey of Children with Special Health Care Needs (NS-CSHCN), 2) the 2002 Healthy Youth Survey,

3) 2003 Behavioral Risk Factor Surveillance System, and 4) participating state agency program data. They learned about the number of children with special health care needs in Washington State, their unmet needs, and priority areas of interest.

## **B. Committees**

Fifty five individuals were recruited by the Department of Health CSHCN Program to serve on the Steering Committee and the four subcommittees. Members included a diverse collection of individuals from programs that support and advocate for children with special health care needs and parent consultants representing different cultural backgrounds and regions of the state. In addition, the Washington Family to Family Network (WFFN) met monthly and provided feedback on WISE Grant draft documents and reports. Its purpose is to promote a quality, statewide support system for children and youth with special needs and their families and to develop a statewide network of diverse family leaders. WFFN was an integral part of the family leadership activities promoted by the WISE Grant. Its members assisted with the planning of family leadership conferences to inform and educate Family Advisory Network (FAN) family leaders about the WISE Grant project goals. WFFN expanded its membership during this time to include the Family Advisory Network and used a parent matching process to provide mentoring to new parents on the WISE Grant subcommittees.

The Steering Committee provided oversight to the activities of the grant and the subcommittees reviewed all available information specific to their goal area. A total of fifty-six committee meetings occurred: twenty steering committees, twelve care coordination, six integrated data, twelve common application, and six blended funding meetings. The steering committee met quarterly throughout the four year grant period and actively reviewed the progress of the pilot sites, assessment, and evaluation activities. Members shared agency updates and provided crucial guidance to the WISE Grant team on grant activities and direction. Family advisors participated in all of the committees and were compensated for their time and travel.

The Common Application Subcommittee was co-chaired by the Project Coordinator and information technology expert. The subcommittee explored examples of common application projects nation wide, invited guests from other agencies to present information, and provided direction for the process of developing a common application system. A concept paper for an Internet based common application system was developed. Committee members also served as liaisons to their own organizations.

The Care Coordination Subcommittee described characteristics of the “ideal integrated system” during WISE grant meetings in 2002-2003. They completed an assessment of the current care coordination system and developed a matrix outlining roles and responsibilities.

The Blended Funding Subcommittee planned an integrated funding conference, Developing and Funding Integrated Delivery Systems, (September 26, 2002) and studied examples of other state efforts to blend funds.

A cross-agency integrated data task force consisting of key data system personnel identified data sources describing the CSHCN population and developed a survey tool which was distributed to state agencies.

## **C. Pilot Sites**

Five pilot communities were selected, including three Local Health Jurisdictions and two Neurodevelopmental Centers. A one-day conference in 2002 was held for pilot site leadership to orient coordinators to the goals and objectives of the WISE Grant.

Communication between pilot sites and goal-focused committees was a priority. Pilot site representatives presented at key subcommittee meetings. The pilot site coordinators met as a group in the summer of 2002 to better understand the goals of the grant, their own roles, and to enhance their relationship with one another and the WISE Grant team. Subsequent to that meeting, monthly scheduled conference calls, regular receipt of all committee minutes, attendance at the Integrated Funding Conference, and consultations with the information technology contractor helped enhance the partnership between the pilot sites as well as increase the pilot site coordinator's knowledge and understanding. Family involvement was included in all aspects of the pilot site development.

### **Cowlitz/Wahkiakum Pilot Site**

In 2003, the Cowlitz/Wahkiakum pilot site (The Progress Center) conducted an assessment of the county's readiness to implement a common application web portal. Primary factors in selecting these counties were: 1) existing centralization of many services at the Progress Center and the local health jurisdictions, 2) progress previously made in inter-program information exchange and intake processes, 3) general accessibility from the Olympia area, and 4) sufficient progress made in proposed workflow processes. Nine targeted programs were selected to participate in the pilot project: Child Care and Early Learning, Children with Special Health Care Needs, Developmental Disabilities, Early Childhood Education and Assistance Program, Head Start, Infant Toddler Early Intervention, OSPI - Special Education, Medicaid, and the Women, Infants and Children (WIC) Program. Primary factors in selecting these programs were: 1) fewer known obstacles, 2) previous success in data standardization, 3) centralized program data systems, and 4) sufficient progress made in proposed workflow processes. Cowlitz and Wahkiakum Counties sustained their community's readiness to participate in developing and testing a web-based system.

### **Yakima Pilot Site**

Yakima narrowed their focus to address the 0-3 population of children with special needs. To address the funding infrastructure of the 0-3 population in Yakima County,

the steering committee prepared a visual and narrative description of multiple funding sources and barriers to blended funding and identified a subcommittee of individuals with fiscal expertise at the community level. The committee also verified with Medicaid the perspectives of payor of last resort and sought a legal opinion and reviewed existing case law. Over the course of the pilot, the Yakima steering committee examined models in other states regarding pooled resources, continued to assess to assure use of payor of last resort (Part C) as drafted by ITEIP, met with local lead agency accountants to assure compliance and verified that further blending of funds for their target population cannot occur without State level support.

### **Grant Pilot Site**

Grant County maintained a list of providers for families and developed a resource referral list for physicians and agencies. They increased access to Part C and Title V Diagnostic and Treatment Funds to fund services for families. Additionally, they broadened the scope of community awareness to the general public, medical staff, community agencies and parents about services available. A common enrollment form for parents to access on-line to improve care coordination was developed.

### **Whatcom Pilot Site**

Whatcom utilized many methods to address the goal of care coordination. The local steering committee convened quarterly meetings and completed a 2002 baseline assessment across the four WISE goals using SIMS. They developed a lead care coordinator model service flow chart and adopted existing definitions of screening and evaluation activities. They identified a lead care coordinator pilot project provider and identified current providers who provide, or could provide, identification specialist services. They also developed and promoted professional standards and forms that were consistently used by lead care coordinators and developed a community resource team. They set up a single entry phone number for families and professionals to call to access a Lead Care Coordinator and formalized mental health services and special access procedures with their local community mental health agency. Lastly, they started to further assess the scope of needs of the families enrolled in the Lead Care Coordination project and the level of service they have received.

### **Island County Pilot Site**

Island County conducted a mini assessment with the Interagency Coordinating Council and parents of children with special needs to determine what their “ideal” parent mentor position would look like, including ideas for training. Parents reviewed funding options, with the agreement that the WISE Grant coordinator would help them complete grant applications. They also identified the need to address funding, supervision, and training for the position. They state that they



intend to obtain, clarify and implement other identified services/changes requested by parents from the WISE grant survey.

## **D. Family Leadership**

The WISE Grant was designed from the beginning to include families as decision makers in all aspects of the project. In the original grant proposal, an existing statewide coalition called the Washington Family to Family Network (WFFN) was described as a key partner in developing family input at all levels. WFFN was already a well-integrated group of veteran family leaders representing children with special needs across several systems, including Washington State Department of Social and Health Services - Infant Toddler Early Intervention Program, Washington State Department of Health - Children with Special Health Care Needs Program, Family Leadership Team of the State Interagency Coordinating Council, Family Voices of Washington, Washington State Parent to Parent, Ethnic Outreach Coordinators of Washington State Parent to Parent, Washington State Fathers Network, The Arc of Washington, Sibling Support Project of Children's Hospital and Regional Medical Center, Medical Home Leadership Network, and Washington PAVE. Mental health issues were later represented by the inclusion of Statewide Action for Family Empowerment (SAFE) of Washington.

First steps towards assuring family involvement at all levels were to engage WFFN as the formal family advisory steering committee for the WISE Grant. WFFN accepted this challenge and immediately accepted responsibilities including recruiting new parents to serve on the Family Advisory Network, orienting, training, and mentoring new family advisors, serving on WISE Grant subcommittees and the Steering Committee as veteran parents, providing feedback on grant methodology, processes and findings, and consulting with the WISE Grant team to plan and implement annual family leadership trainings.

In 2001 WFFN recruited parents to serve on the WISE Grant subcommittees. WFFN set the selection criteria, focusing on developing a diverse group of new parents who could provide a fresh perspective on the issues. Criteria included age of children (0-12), diagnosis, gender of parent(s) and ethnic, racial and geographical diversity. Recruiting was done through application packets developed by WFFN and mailed statewide to a list of diverse parents who had previously been in contact with WFFN and had expressed interest in family leadership. The opportunity was also advertised broadly through WFFN members' websites and email services. WISE Grant goals and FAN responsibilities were described. Twelve parents ultimately applied. The WISE Grant required only four parents, one for each subcommittee. WFFN screened each applicant and ultimately decided to invite all 12 to become involved at the level that suited the parents. This required WFFN to develop a process to engage all 12 parents in orientation and mentoring. It also required the WISE Grant family leadership monies to become a blended funding experiment



in its own right. Over the four years, several WFFN partners, including ITEIP and Medical Home, as well as the National Center for Cultural Competence and Champions for Progress Center, provided blended funding (in-kind, technical assistance or monies) for leadership training, hotel costs, and parent stipends. Through this process, not only the original 12 parents were involved, but steering committee parents from the local pilot sites, Medical Home Leadership Network parents, Parent to Parent coordinators and helping parents, parents from diverse ethnic groups who work with children with special health care needs, and parents whose children have primarily mental health challenges.

Some of the new Family Advisory Network recruits chose to be primary members of a subcommittee or the Steering Committee, and others chose to be alternates. Veteran parents from WFFN assigned themselves to subcommittees too, and committed themselves to act as mentors to the new parents.

A series of orientations and trainings was provided to the WISE Grant family leaders at the state and local levels. Integration of parent leaders working on similar issues in different parts of the state has been a goal. Trainings for parents and family members included:

February 2002	Initial Family Advisory Network Orientation and Training
September 2002	Developing and Funding Integrated Delivery Systems
February 2003	Getting to the Heart of Family Centered Care for CSHCN
November 2003	Taking a Leadership Role in Developing Family/Professional Partnerships
September 2004	Getting out the Word and Bringing in the Partners (Social-Marketing)
November 2004	Family Leadership Institute

Strategies used at the family leadership conferences have been documented in toolkits which the parents continue to use. The trainings have encompassed a number of strategies to develop competence, confidence, and family-professional partnerships, including WISE Grant, Title V, and Medical Home orientation, connection with veteran parent mentors and professionals, WISE grant updates, parent feedback on WISE issues, cross-fertilization of ideas between parent partners working on parallel projects throughout the state, infusion of cultural competence principles, and other topics. Each year, the family leadership conferences have accommodated more parents. The core group of family leaders continues to grow.

At both the state and community level, participation and satisfaction have been measured in evaluation surveys, interviews, and minutes for state and local steering committees. Parents provided input on the WISE Grant logic model and evaluation framework, validated short-term evaluation results, reviewed strategic planning and proposed integration strategies. Parents also participated in focus groups, evaluated trainings, and provided qualitative information for future integrated systems development.

**Practical Tips:** After one year of involvement in the WISE Grant, Family Advisory Network members provided feedback to WISE Grant team members regarding strategies that they found most helpful as a new family consultant. Based on this work, the WISE Grant team developed a document called “Practical Tips: Involving Family Consultants in Program and Policy Development.” The document contains simple tips to increase the ability of diverse family advisors to participate effectively on policy committees. It has been used to facilitate the involvement of parents in family advisory roles not only within the WISE Grant but within other contexts as well. Examples of its use include local WISE pilot sites, where steering committees were contracted to use the document and report on its effects; at the local level with CSHCN Coordinators and Parent to Parent Coordinators; and with the Healthy Mothers, Healthy Babies On-Line Access Project, where family consultants from the WISE Grant are now engaged in assisting that effort.

**Champions for Progress Center Family Leadership Institute:** Assuring that family leaders will be prepared to take the WISE Grant recommendations to the implementation phase is a key goal of the WISE Grant family leadership conferences. In November 2004, the CSHCN Program held the largest of its WISE Grant family leadership conferences. The Family Leadership Institute involved 40 family leaders from around the state. This final WISE conference was supported by a grant from Champions for Progress, and significant contributions from ITEIP, the National Center for Cultural Competence, Family Voices, Sound Options Group, Advanced Approach, and WFFN. The conference focused on raising awareness of the six CSHCN National Performance Measures among family leaders as well as giving families the opportunity to learn new ways to have difficult conversations. Family leaders are ready to work on next steps to see the WISE Grant recommendations implemented. Some will work at the personal and community level to improve systems of care, while others are interested in serving at the state policy level. Their next steps are being integrated into the WFFN vision, mission, and long range planning that have evolved as a result of the WISE Grant. WFFN and FAN next steps are being incorporated into the CSHCN Program’s Family Leadership Plan.

## **E. Social Marketing**

It was recognized early in the grant period that proposing a system-wide change would require a marketing component. The 2004 social marketing conference provided stakeholders with a foundation in social marketing principles along with approaches and techniques needed to market a web based common application system both locally and statewide. The name CONNECT was developed to use in this proposal. Based upon the outcomes from the social marketing conference with Health Systems Research, Inc., stakeholders reported a strong need to launch a social marketing campaign once the web-based common application portal was ready for use.

## F. Evaluation

A revised WISE Grant evaluation framework was developed in August 2002 with guidance from an evaluation workgroup. This workgroup consisted of local and state WISE Grant stakeholders, an epidemiologist, evaluation specialists, and parents. After reviewing the proposed evaluation strategies in the original WISE Grant application, the workgroup recommended the following changes: delete initial surveys in local communities, develop a logic model, validate or refine the four goals, and develop clear evaluation strategies.

As a result of that evaluation workgroup, a logic model including measurable objectives and action steps was developed. The logic model allowed stakeholders and staff to formulate questions to address implementation and effects of the project. After the logic model was developed, the purpose of the evaluation was clarified to include:

1. Gain insight into how the WISE Grant is functioning at the local and state level.
2. Improve WISE Grant functioning and fine-tune the process to determine effects of the WISE Grant.
3. Involve participants in the evaluation process and engage stakeholders.

After the logic model was finalized, a strategic action plan was developed to outline the major activities and tasks for the grant. This document guided the work of the grant and determined what methods would be used to study the feasibility of the four goals and the process for developing the recommendations for integrating services for children with special health care needs.

In 2002, as part of a WISE Grant short-term evaluation, parent advisors from WFFN and FAN reported that although information and resources are available, they do not know how to locate them. A common application system would bring all of the information and resources into one place, allow families to apply for services on-line and improve outcomes for both families and professionals. They also strongly suggested that the common application goal was the most important for families.

In 2003, WISE Grant members were surveyed to address the following evaluation topics: 1) Were expectations about participating in the WISE Grant activities met? 2) Identify one or more areas in which the WISE Grant team can improve future activities and outcomes of the grant. 3) Describe what has changed for you or your agency since beginning your work on the WISE Grant. Eighty two surveys were mailed. Thirty three surveys were completed. Of the 33 completed surveys, 11 were State agency staff; three were local pilot sites, six FAN/Parents, one alternate FAN, three providers, six other. Five respondents were unidentified.

In fall 2004, an evaluation of the pilot sites was completed by Organizational Research Services to synthesize the learnings of the pilot site projects and findings

from the state-level System Assessment Report. This included pilot site experiences, successes, challenges, and outcomes while implementing integration goal areas, overall outcomes achieved by the WISE Grant project, general observations to successful service integration for local systems of care, and recommendations for next steps.

In summer 2005, a final WISE Grant member evaluation will occur to re-examine evaluation questions that were administered in 2003. Also, additional outcomes will be identified by members and shared at the July 28th WISE Grant recommendation wrap-up meeting.

## IV. Findings and Progress Made on the Four Goals

The findings for this report were derived from several methods of study including needs assessments, committee research, pilot site projects, family leadership, social marketing and evaluation.

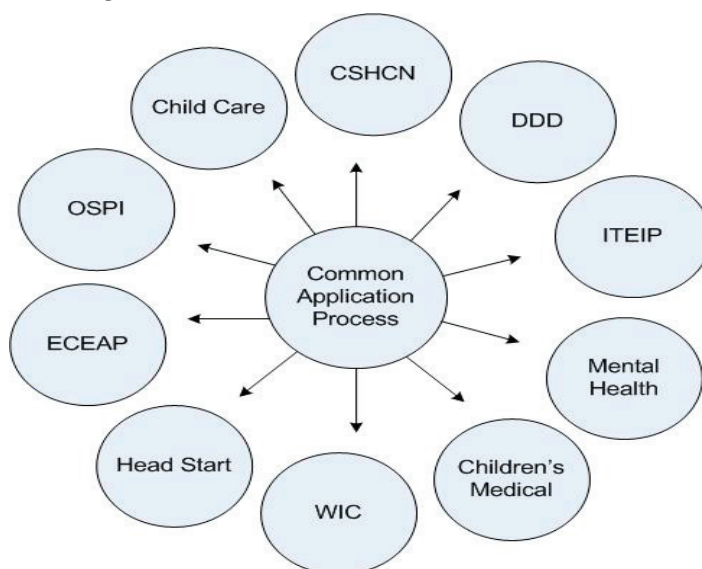
### A. Needs Assessments Findings

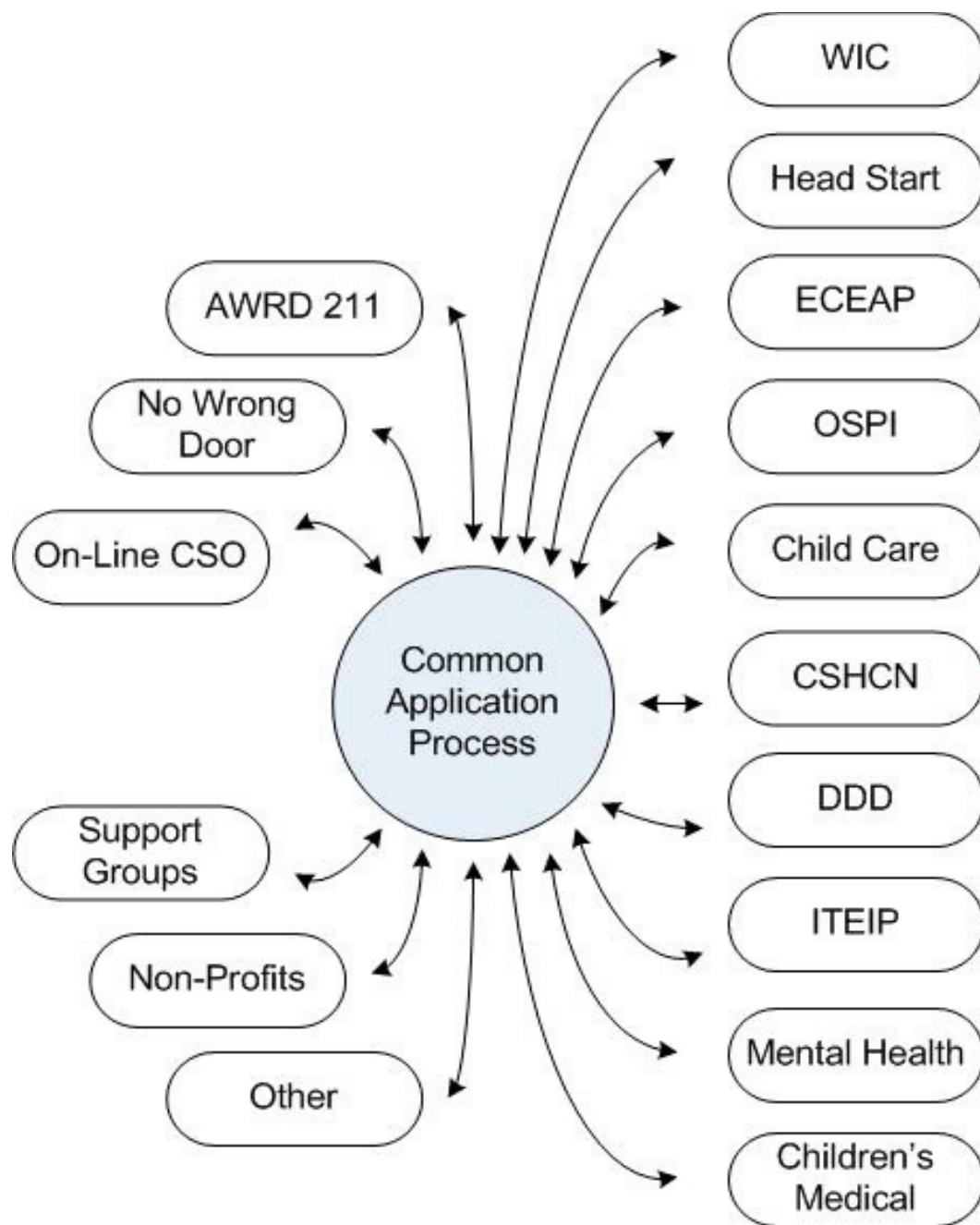
#### 1. Findings from the 2002 Common Application Assessment

Findings from the 2002 Common Application Assessment included the following:

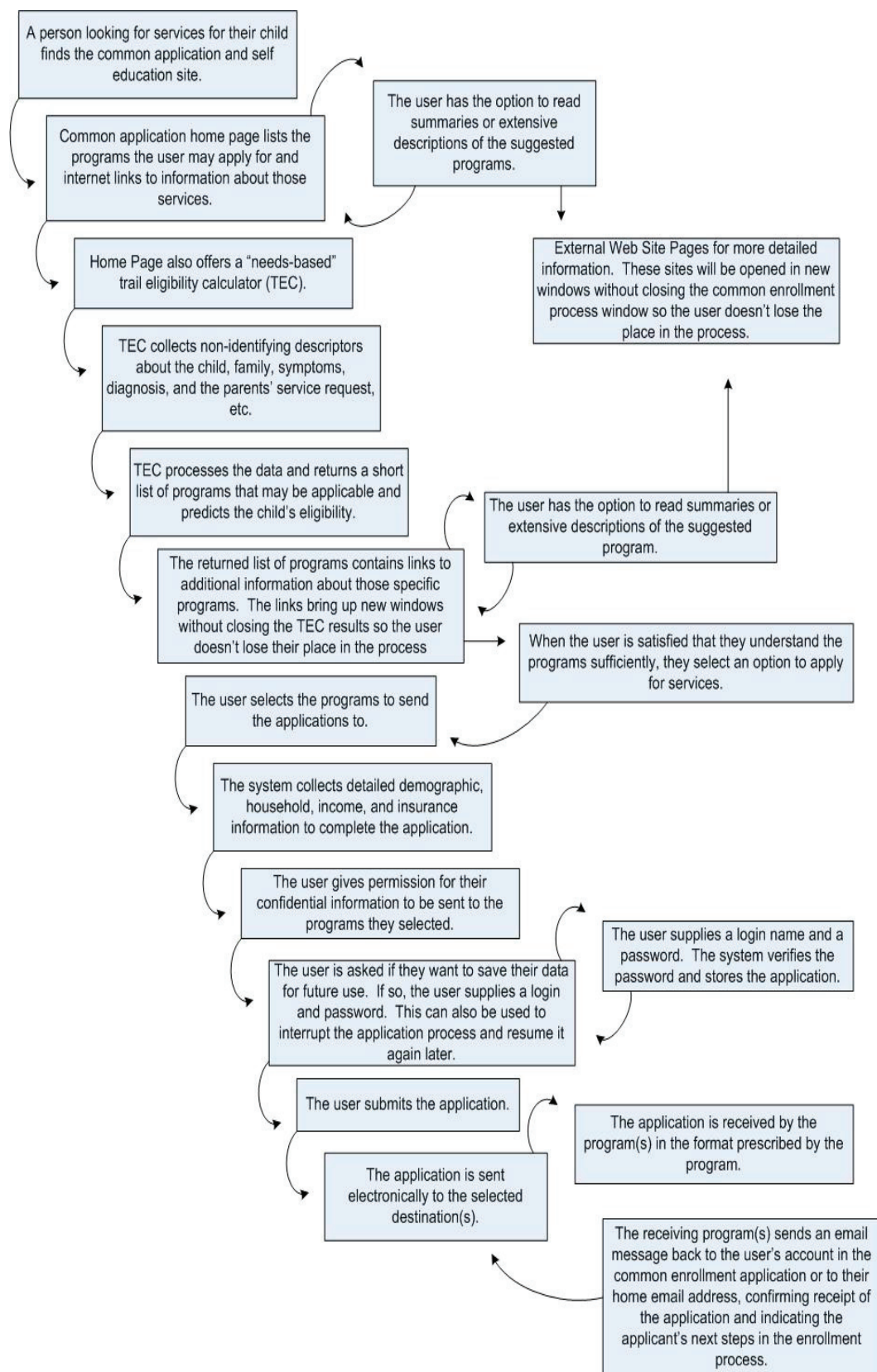
1. Define and conduct a pilot technology project that will accomplish the objectives of common and simplified application combined with a user-friendly and easily navigable system for information and education of government programs.
2. Postpone further investigation into a common care coordination system until the general environment is more open to the concept and this could be successfully accomplished.
3. Form a task force to define and prioritize the needed assessment information. This definition would then be compared to the information that can be obtained from the DSHS Office of Research and Data Analysis (ORDA) data bases and other existing data sources. This comparison will define the “missing” assessment information. The value of the missing information could then be compared with the cost of developing a data warehouse or augmenting the existing data sources sufficiently to provide the missing information.

The 2002 assessment of the Common Application process concluded the need to develop visual diagrams that would outline the information flow from the user to the local service provider. Following are three diagrams that outline the information flow.









## 2. Findings from Assessment of Components of an Effective State System

In 2002-2003, research was conducted to identify ideal components of an effective state system. A grant research intern conducted the assessment<sup>1</sup> and concluded that descriptions of ideal models of care for families of children with special health care needs include the following components:

- Multiple points of access for families.
- Complete inventory of community resources that are available.
- Thorough and ongoing assessment of family needs and stressors conducted by multidisciplinary team that includes continued monitoring for families not currently eligible for services.
- Provision of a service coordinator who is able to effectively listen to and understand the families' needs in addition to being very knowledgeable about available community resources.
- All services and assessments must take into account unique family characteristics (i.e. family culture).
- Collaboration between families and their service providers is required.
- Transitions can be extremely difficult and disruptive to families and children. An ideal system strives to reduce transitions as much as possible between birth and 18.

## 3. Findings from the 2002 levels of integration for all Pilot Sites

**Table 1. 2002 Pilot site levels of integration for each WISE Grant goal**

	<b>Common Application</b>	<b>Integrated Data</b>	<b>Care Coordination</b>	<b>Integrated Funding</b>
<b>Island</b>	Cooperation & coordination	Cooperation & coordination	Cooperation & coordination	Cooperation & coordination
<b>Yakima</b>	Integration	Integration	Integration	Consolidation
<b>Whatcom</b>	No connection	No connection	Cooperation & coordination	Information sharing & communication
<b>Progress</b>	Cooperation & coordination	Information sharing & communication	Information sharing & communication	Cooperation & coordination
<b>Grant</b>	Information sharing & communication	Information sharing & communication	Cooperation & coordination	No connection

1. Integrated Service for Children with Special Health Care Needs: A Report on Recommendation, State Systems and Tools for Success. Anne Chestnut, WISE Grant Research Intern, Washington State Department of Health, 2003



### Definitions of table terms

**No connection** = service systems operate independently of each other

**Information sharing & communication** = service systems operate separately, yet communication may occur.

**Cooperation and coordination** = separate agencies loosely organize to work together

**Collaboration** = agencies partner and view one another as equals to provide services for common outcomes.

**Consolidation** = An umbrella organization has identified a leadership structure and administrative functions are centralized.

**Integration** = A fully integrated system that has single authority to address individual child and family needs.

## 4. Integrated Funding Assessment

Key findings from the assessment conducted by the funding consultant on methods for developing and funding an integrated system include:

- Develop a vision for the system.
- Political will is critical to successful funding redesign.
- Individuals can make a difference in funding integrated services, money is a powerful incentive.
- Collaborative funding has not been designed but evolved opportunistically.
- Comprehensive, flexible funding approaches are essential to support more optimum comprehensive systems of care.
- It is important to consider the scope, scale, and duration of activity while keeping the efforts close to families.

## 5. Systems Assessment Findings

Common global themes that emerged from interviews with managers and staff at Washington State agencies included:

- Models for integrating services must be specific and have clear action steps in order to know if they can be implemented.
- Many programs must adhere to federal guidelines and laws that mandate service requirements.
- There are formal processes that allow state law (RCW) and regulations (WAC) to be changed to achieve integration.
- One agency or an interagency oversight committee must be designated to implement and direct integration of services for children with special needs.

Goal specific themes resulting from the systems assessment included:

**Common Application** – Families will learn about resources and complete a single application form when required for public services specific to children with special health care needs. The application should include features that would:

- Specify for which public services families may apply using a common application.
- Develop a list of the core data elements and definitions required for common web-based application.

- Assure that all state agencies' application processes, eligibility criteria, and child enrollment procedures are clear, documented in writing, and coordinated via contract, agreement or rule, with local subcontractors and/or agencies.
- Develop and implement a sustainable system to train agency staff to collect, analyze, and use application data. The training should include concepts related to application processes vs. eligibility criteria.

**Data Integration** – Data relevant to children with special needs from existing public agency data bases will be linked. This would be accomplished when agencies:

- Write a policy statement specifying what application and service data to collect and use.
- Assure data collection procedures at each agency are clear, documented in writing, and coordinated via contracts or rules or agreements with local subcontractors and/or agencies.
- Promote the use of existing intra-agency data sharing agreements among departments and divisions of each relevant public agency.
- Promote the use of inter-agency data sharing agreements and the Institutional Review Board process to share data about children with special health care needs among agencies.

**Care Coordination** – Families will have a single care coordinator to help facilitate and coordinate service from multiple service agencies. To do this, agencies must:

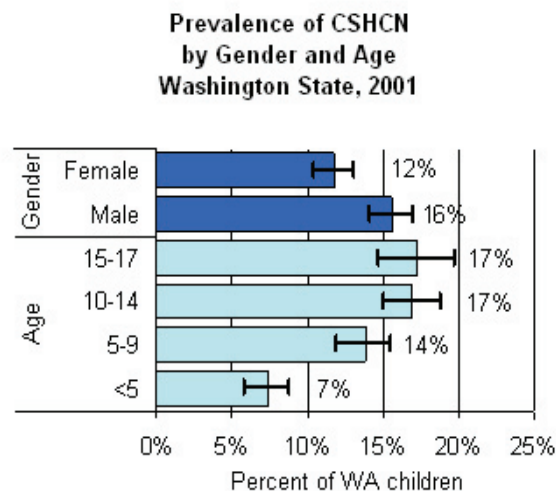
- Develop and implement a plan to promote complementary language in RCW and WAC related to care coordination in various systems in state agencies.
- Assure that those who coordinate care are the bridge to resources for families.
- Coordinate and further develop existing web sites that provide information about care coordination.
- Develop a joint ongoing training for those who coordinate care for children and families to assure each is aware of the roles, resources, and information available.
- Many families must adhere to federal guidelines and laws that mandate service requirements.

The system assessment also revealed that fiscal impact was most frequently mentioned as a perceived barrier. It is possible interviewees who held this view felt the proposed strategies would require increased funds to implement and maintain, rather than resulting in cost cutting measures. This view must be reconciled with the view that decreasing funds are driving service integration and might be explored as a first step in planning for implementation. The cost to change system processes can be weighed against the cost to continue without integration.

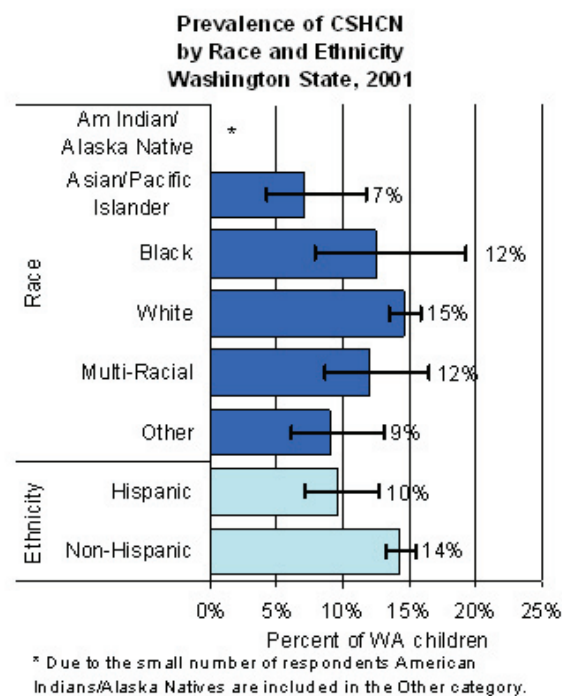
## **6. The Population of Children with Special Health Care Needs**

After studying the population of children with special health care needs, WISE Grant participants determined that according to the National Survey of CSHCN,

Washington children younger than five years had a lower prevalence of special health care needs than school-age children. This finding may result in part because many needs, such as Attention Deficit Hyperactivity Disorder and asthma, (the two most prevalent pediatric chronic health conditions), may not be identified until children enter school. Males are also more likely to have a special health care need than females. These Washington prevalence patterns mirror those of the United States as a whole.



In addition, WISE Grant participants reviewed estimates from the National Survey of CSHCN on race and ethnicity, which indicated that non-Hispanic children are more likely to have a special health care need than Hispanic children, with rates of 14% compared to 10%, respectively. Asian children (7%) are significantly less likely to be identified as children with special health care needs than white children (15%). Differences between prevalence rates for other racial groups are not statistically significant.



Data from the National Survey of CSHCN also indicated that about 30% of children with special health care needs in Washington State live in families with incomes less than 200% of the federal poverty level. National data show that children living at or below poverty have an increased prevalence of special health care needs. These data have not been adjusted for other risk factors, however.

## **B. Sub Committee Findings**

### **1. Common Application Subcommittee**

#### **Key Findings**

- Most public agencies ask for similar information to determine eligibility for services.
- Each state program has different processes for gathering similar information which makes the system difficult to navigate.
- Barriers in policy and law, including eligibility, entitlement, confidentiality, and federal law precedence still need to be addressed.
- Eligibility may differ for each service — some are entitlements and some have criteria.
- Public agencies must agree on a basic set of data elements and method for transferring information.
- Federal, not state laws, dictate policy and procedure for some service.
- There are federal and state laws that govern client confidentiality.

#### **Subcommittee Recommendation**

Design a web based common application to facilitate access to existing state and local resources for children with special health care needs and their families, professionals, and all who work with children. Families will be able to complete a single application form for public services specific to children with special health care needs.

### **2. Care Coordination Subcommittee**

#### **Key Findings**

- Care Coordination for CSHCN in Washington State is fragmented.
- In many cases, a child's care coordinator coordinates only portions of the scope of services that the child uses.
- In many cases, children have multiple care coordinators from multiple agencies who may not communicate with each other.
- The term "care coordinator" has different meanings among agencies.
- Families state a desire to have a primary care coordinator who helps them navigate the system.
- Many of the policy and procedure barriers can be addressed through increased communication and collaboration across local agencies.

#### **Subcommittee Recommendations**

- Agencies that have care coordinators will have evidence of a commitment to the process of sharing services offered, i.e. interagency agreement, memorandum of understanding, or shared funding.

- Agencies will agree to have training requirements for all care coordinators/case managers that include knowledge about other agencies.
- Trainings on care coordination and the role of agencies will be developed by care coordinators from listed agencies through sharing materials and agreeing on referral strategies. Trainings will be conducted for care coordinators of listed agencies.
- An evaluation plan will be developed.
- A sustainability plan for ongoing trainings will be established.
- Develop a care coordination matrix which outlines roles and responsibilities of care coordinators in all agencies who serve children with special health care needs.

### **3. Integrated Data Subcommittee**

#### **Key Findings**

- Agencies must commit to data integration as a long term agency goal.
- There needs to be data sharing agreements among departments and directors of each relevant public agency.
- Each local subcontractor has different procedures and possibly different software for collecting and maintaining data.
- There needs to be a clear statement that specifies what data is to be collected and how it is to be used.

#### **Subcommittee Recommendation**

An internal commitment to integrate data is an essential first step before cross agency data integration can be implemented.

### **4. Blended Funding Subcommittee**

#### **Key Findings:**

- It is possible to find funding that is flexible to support efforts to meet local needs.
- Early and strong buy-in from major stakeholders is essential.
- Political will is critical to successful redesign of collaborative funding.
- Comprehensive, flexible, thoughtful funding approaches are essential to support more optimum comprehensive systems of care.
- Keep efforts close to the people being served.
- Blended funding is closely linked to the other three goals.
- The concept of blended funding is extremely difficult to address at the state and federal levels.
- It was decided early in the WISE Grant to focus on the other three goals.

#### **Subcommittee Recommendation**

Blended funding is happening at the local level but is more difficult to accomplish with state and federal funds. Whenever possible, agencies should combine funds for

cross agency activities, such as trainings. The blending of funds supports the other three goals of the WISE Grant.

## **5. Washington Family to Family Network (WFFN) Committee**

### **Key Findings**

- Families support the development of a multi-dimensional web portal that allows them to access information, complete a common application, and connect with other supports.
- Integrated options for 211 telephone access, knowledgeable, compassionate parent mentor/navigators, and paper copy access for those without a computer are essential aspects of an integrated web system.
- Families want a lead or primary care coordinator to assist them in navigating the system especially during stressful periods such as early diagnosis. They want the ability to choose their primary coordinator from a group of highly qualified professionals or parent navigators and change coordinators as the needs of the child or family change.
- Families want providers to know more about available resources. Providers who are unsure of resources tend not to refer. Families think an integrated web portal will benefit providers by giving them access to the same information that families need.
- The common application web portal should never turn people away empty handed. At minimum, families should receive family support resources and other information such as Parent to Parent, Fathers Network, and Ethnic Outreach program regardless of income.
- A social marketing campaign to make the public aware of the services and broad visibility is essential to success.
- Neighborhood access to the web portal through libraries, community service offices, doctor's offices, and other places is essential.

## **C. Pilot Site Findings and Progress on Goals**

Five counties in Washington State piloted integration strategies for the WISE Grant. This section briefly describes the projects and outlines findings and outcomes specific to each goal.

### **Common Application**

*“Power is in the parents’ hands...it’s not about what the agencies think the parents need. The common application truly gives the power to the parents.”* Pilot Site Representative

## **Cowlitz and Wahkiakum Counties**

### **Project Description**

Progress Center, an early intervention center for children with developmental delays, convened the pilot process in Cowlitz and Wahkiakum Counties. The group's goal was to develop a web portal for parents, guardians or family members to find services for children with special health care needs. The site would list current services provided, which programs would be most applicable to families, and whether children and families would be eligible for services. The web-based model was new for the area and proved to be the key to developing a common application on which all the stakeholders could agree. In the past, agencies could not agree on a standard format for a common application, but the web portal technology allowed agencies to keep their own identity and integrity intact while still accessing the benefits of a common application. The new technology of the model alleviated turf battles.

### **Keys to pilot success include the following**

Tremendous up-front involvement in developing software and hardware. Each of the participating agencies could see the future benefits of the system and were willing to invest the time required to develop the portal. The end product was designed to be accessible by anyone, anywhere.

The project was not owned by any one agency. Parents do not need to be connected with a single agency to access the application and could even access the site by phone via the Healthy Mothers, Healthy Babies line.

The application is adaptable; information can be added depending on the needs of the local community.

### **Outcomes**

Outcomes identified by pilot site representatives include the following:

- Increased parent involvement.
- Increased diversity of agencies working together toward a common goal/product.
- Increased focus by agencies on children with special health care needs.

### **Moving Forward**

Though the hardware and software issues of the web portal have been addressed, the strategy was not implemented due to lack of funding. Therefore, there were no direct impacts on children with special health care needs and their families. If this goal area were implemented, it is anticipated that there would be increased knowledge of available services and greater access to services for children with special health care needs.



## **Island County**

### **Project Description**

Island County began the process of creating a common application before the WISE grant in response to complaints by parents. It took about one year to develop a form that was acceptable to all agencies; currently about half of the local agencies use this form as a part of their standard procedures. Focusing local agencies regularly and consistently on the “parent as customer” concept helped to break through barriers to create and adopt the form. Privacy issues were another challenge to the form development; however, as agencies worked together and developed more trust, they became more willing to share and work cooperatively to address these issues. It was also important to local agencies to use the terminology “Enrollment Form” rather than “Common Application” because the latter term implied that the child already qualified for programs.

### **Outcomes**

Through the development and adoption of the common enrollment form, the project has had a positive impact on children with special health care needs, including the following:

- Decreased time needed to make referrals for children.
- Increased efficiency of the referral process.

### **Moving Forward**

Some barriers to the common enrollment form strategy still exist. One obstacle to full adoption has been staffing changes within agencies, even though agency personnel who adopt the form report that it is easy to use. Additionally, office staff members filling out the common enrollment form are not always qualified to make appropriate referrals for families. Some local organizations have also been reluctant to adopt the form due to internal policies and regulations. While the common enrollment form helped increase reciprocal referrals, the systems are not integrated. Agreements are largely informal and verbal, and agency implementers are still more likely to call a known person for a referral to another agency rather than filling out the form.

Island County initially focused on the creation of this form as its integration strategy, but the county ultimately concentrated on identifying and addressing other parent priorities, including researching funding for a parent mentor position, respite care, increasing parent involvement and community awareness.

### **Care Coordination**

*“Entering the system can be overwhelming for parents. It’s a whole new world. Agencies are now taking on care coordination. This helps parents focus on what is important—being a parent. Parents felt a burden for*



*many years to be the provider, the family resource coordinator, the physical therapist, which left very little time to parent.” — Parent*

## **Grant County**

### **Project Description**

Grant County worked to create a successful collaboration environment to promote efficient use of services and resources, enhance the transition process for clients/families, and minimize the duplication of services. They accomplished this by working through the County Interagency Coordinating Council. Through this group, the County identified what was working well, what barriers the agencies chose to address and enhanced awareness of local services and resources through regular updates to local agency representatives.

### **Key Accomplishments**

Increasing awareness across agencies was a major focus of the project. The pilot process successfully strengthened existing partnerships and streamlined communications. Through the collaborative efforts of agencies, providers became more aware of services offered by other agencies and could more easily provide appropriate referrals in a timely manner. Another key project success emerged from addressing a barrier regarding physician referrals. In the past, referrals had come to the Health District through other agencies. By connecting with local physicians through the medical home concept, county health staff now regularly meet with physicians to coordinate care. “Medical home” refers to a team approach to providing primary health care services in a high-quality and cost-effective manner. In a medical home, the child or youth, his or her family, primary care physician, and other health professionals develop a trusting partnership based on mutual responsibility and respect for each other’s expertise. Together, families, health care professionals and community service providers identify and access all medical and non-medical services needed to help the child and family. Medical homes are especially important for children with special health care needs and their families.

### **Outcomes**

The project has had positive impacts on children with special health care needs. A site representative believes that one-quarter to one-third of local families of children with special health care needs have been involved with or benefited from the project.

Outcomes include the following:

- Increased efficiency of referrals and services.
- Increased access to services.
- Increased awareness and knowledge of available services and resources.
- Increased parent support and networking.

- Increased parent leadership. Several new parents who became more involved in the project are now spearheading committees for the Interagency Coordinating Council.
- Increased utilization of services for their children. Because this area is a rural community, there are not necessarily more services for individuals to access, but the pilot representative believes that more children are receiving services than before the pilot project began.

Local agencies experienced several outcomes:

- Increased knowledge and awareness of services available and the agencies that provide these services.
- Increased collaboration. Providers are more willing to take initiative to provide what families need rather than be constrained by strict roles.
- Increased awareness of the needs of families with children with special health care needs as a result of the education and public awareness efforts.
- Improved attitudes toward integration. While the county already had a fairly high level of collaboration before the grant process, some agencies have begun to participate more fully.

## **Whatcom County**

### **Project Description**

Whatcom County developed and implemented a Lead Care Coordination model that focused on developing an identification continuum and providing care coordination for children with special health care needs and their families. Through this model, families are identified and referred to the Lead Care Coordinator housed at a local Family Support Center. The Lead Care Coordinator meets with the family and completes a more comprehensive intake. When a family has a complex level of need, the Care Coordinator assembles the Intensive Team, a case-specific group of representatives from local agencies that decides how they, as a group, can meet the varied needs of the family. In the past, families would go from agency to agency to get piecemeal support. This streamlined process provides continuity for families. The Lead Care Coordinator can follow up with parents, ensure families receive needed services, and help families meet their goals. A matrix/flow-chart has been created to illustrate this process.

### **Key Accomplishments**

The development and implementation of the Lead Care Coordination model has been the most powerful accomplishment of the pilot process in Whatcom County. The community has expanded its ability to meet the needs of the family in a coordinated manner. Each agency knows what services other agencies provide and can better identify the most appropriate connections to support each family.

*“If you think about a patchwork quilt, if we’re going to cover families with the quilt, each one of us will be a square on that quilt. Before, we may have thought that we could do this [ourselves]. We can help them get what they need. Now it’s more like, I better pull over this part of the quilt, and I have to wrap in this part of it over here to make it work.”* — Pilot site representative

## Outcomes

Outcomes for the families and their children identified by those involved in the pilot process include the following:

- Increased support for families. By having a Lead Care Coordinator, families can have hope and feel that their needs will be met.
- Better coordinated services for children.
- Increased services received by children.
- Earlier identification of needed services for children.
- A more welcome and open environment for families.

A number of outcomes for parents were also identified:

- Decreased isolation for parents.
- Increased involvement by parents. Parents on the Steering Committee contributed to the design of the model and identified areas that had been fragmented in the past. In addition, new parents have participated in Interagency Coordinating Council meetings.
- Increased satisfaction with services.

Outcomes were also identified for local agencies:

- Increased collaboration. Through the process of researching and designing the process, agencies have strengthened relationships and built trust across agencies.
- Improved communication across agencies.
- Increased coordination in support of families. Agencies blend responsibility to support families as a community of providers.
- Increased positive attitudes toward integration. Although there was support for better coordination before the pilot, this project further raised awareness about the importance of integration among local agencies.

## Moving Forward

Awareness of the Lead Care Coordinator model still needs to be built across the general population through flyers or public service announcements (PSAs). If families know that agencies can meet their needs in a coordinated manner, they might be more likely to communicate their issues, have more issues identified, and receive necessary services sooner.

## **Island County**

### **Project Description**

While Island County initially tackled the development and adoption of a common enrollment form, they also focused on identifying and addressing parent-defined gaps or needs in the local care system. To do this, Island County engaged parents in three focus groups to develop a list of priorities. The groups identified five priorities: parent support (including a funded parent mentor position); respite care coordination; school districts; health care provider referral and counseling; and community awareness/integration into community activities. After drafting this list, the county surveyed additional local parents to determine the highest priority. This feedback helped create the Parent Mentor job description. The Parent Mentor would be the parent of a child with a special health care need, and would be paid to assist other parents with Individualized Family Service Plans (IFSPs), Individualized Education Program (IEPs), speaking with doctors, transitioning to new schools, and giving up-to-date resources to families. The Parent Mentor would also help address gaps that occur during the summer, a time when school resource people are unavailable and few activities are planned for the special needs population.

### **Key Accomplishments**

Though the Parent Mentor position is still unfunded, the process of developing the parent priority list led to an increased focus on parents' needs. The County Interagency Coordinating Council still regularly references the list of parent priorities at its meetings. As their issues have been brought to the table, parents have become more motivated and empowered to address their own priorities. For example, parents wanted to have a retreat for mothers of children with special health care needs. The parents organized the retreat, and local agencies cooperatively provided funding to support the event.

### **Outcomes**

Through the ongoing process of engaging parents and prioritizing their concerns, Island County has achieved a number of outcomes, particularly for parents and local agencies.

Identified parent outcomes include the following:

- Decreased parent frustration with the care system.
- Improved parent ability to access information.
- Increased parent satisfaction with the care system.
- Increased creativity for solving problems within the care system.
- Increased focus on parent needs/perspective rather than agency needs/ perspective.
- Improved attitude toward collaboration and the care system.

Through the development of the list of parent priorities, the Island County Health Department began working with the school district to offer a class on Individual Education Plans for parents. This class has played a significant role in the following parent outcomes:

- Increased parent knowledge and understanding of the school system and services provided for children with special health care needs.
- Increased parent activity and involvement with the school district.

### **Moving Forward**

Though parents are still sometimes frustrated with the amount of time needed to move forward on the identified goals, Island County is making progress toward achieving them. One continuing challenge has been securing funding to implement parent priorities, such as the Parent Mentor position.

### **Blended Funding**

*“When families come through the door of an agency, they want to know that they’re going to get the best possible services for their child and don’t care about specific cost centers and where the funding is coming from for each program. It is nice for families not to worry about this.” — Parent*

## **Yakima County**

### **Project Description**

Children’s Village in Yakima focused on blending funding to better support families and meet their needs. The ability to blend funding or find more flexible funds allows agencies to provide more continuity of services. Though the complex and technical nature of this goal area makes it more difficult to address, families are negatively impacted when services are unavailable and needs are unmet.

### **Key Accomplishments**

The most powerful accomplishment in this goal area was engaging broad community involvement. Children’s Village convened representatives from a wide variety of local agencies, including representatives from Yakima County (the County Commissioner and Director of Yakima County Human Services), the local Educational Service District (ESD 105), Enterprise for Progress in the Community (EPIC), the regional office of the Department of Social and Health Services (DSHS), and Columbia Legal Services. Each local agency willingly reviewed its own systems and funding in detail to identify opportunities and barriers. Through this process, all partners increased their knowledge of the rules and regulations of each funding stream and developed clarity about Payor of Last Resort terminology. Ultimately, the partners were able

to develop a funding matrix tool that represented funding streams, the services they cover, fiscal and program reporting structures, and other relevant information.

*“We have identified how important it is to have consistency in services through consistency in funding....”* — Pilot site representative

The focus on blended funding has helped to bring awareness to the community of the importance of continuity of services and funding for children with special needs and their families. Children’s Village also believes that flexible funding can lead to better outcomes for children and their families. While there were limitations to the group’s ability to integrate or blend funding because of state- and federal-level regulations, Children’s Village was able to find ways to access funding that is more flexible, including securing contracts with school districts, tapping the donor community, and obtaining funding through the Memorial Foundation.

### **Outcomes**

Several outcomes have been identified for children and their families through the flexible funding model used by Children’s Village:

- Increased continuity of services. Flexible funding supports internal capacity to continue providing needed services for children when other funding streams dry up.
- Increased services available, including hippotherapy (i.e., equine therapy) and special education teachers.
- Increased referrals for services.
- Increased support for children and families, including non-therapeutic resources such as mileage and lodging support for families traveling to receive services.

The primary outcome identified for parents was increased support. Flexible funding from local community donors allowed Children’s Village to stabilize funding for its family centered service model, including the Parent to Parent Program. This program provides emotional and informational support to parents of children who have special health care needs by matching families seeking support with experienced, trained “Supporting Parents.” Parent to Parent is institutionalized across Children’s Village to provide parents with universal access. If Children’s Village had to rely solely on the current funding and regulations, parents would not have the same level of access to this high quality program.

A number of outcomes were identified for local agencies:

- Increased local investment in meeting the needs of children with special health care needs and their families.
- Increased knowledge of services that local organizations provide.
- Increased knowledge about current local practices, funding requirements, and funding possibilities and limitations.

- Increased knowledge of specific issues, such as Payor of Last Resort.
- Increased willingness to problem-solve.
- Changes in resource allocations as flexible funding options were identified.

### **Cross-Site Outcomes**

In addition to pilot site-specific outcomes, several cross site outcomes were revealed which related to the WISE Grant as a whole.

#### **Agency/System Level Outcomes**

- Increased collaboration among local agencies and organizations.

All sites agreed that collaboration had increased through the process of working on integration goal areas. While all the pilot site communities had a history of local collaboration, site representatives agreed that having a formal process and goal through WISE grant involvement supported local efforts. In particular, hearing the message from the state to support integration helped defuse local turf issues. The process also brought new partners to the table in many communities. Finally, dedicated funding for staff time to focus on integration and collaboration supported the success of the grant.

- Increased communication across agencies.

All pilot sites also noted that cross-agency communication had increased. In many areas, coming together around a common goal helped ensure that agencies knew what services different organizations provided and how local agencies could collectively support families. By increasing local knowledge of available services, as well as gaps in services, agencies could better support families and children with special health care needs.

- Increased efficiency of local care systems.

Four of the five pilot sites specifically noted that parts of the local systems supporting children with special health care needs and their families had become more efficient. These changes included decreased time for referrals and earlier identification of services to support children and their families. Much of this progress resulted from increased communication among local partners. By better knowing what services were available, any provider could more efficiently refer children and families to services and also identify if a child's needs could be met by another local agency. A related prioritized outcome for the WISE Grant was to decrease the number of service systems parents encounter. Though the streamlined referral and identification processes in some communities resulted in increased efficiencies for parents, communities did not necessarily decrease the number of service systems parents encountered. This type of outcome would require more formalized integration of data systems and procedures across service providers.



### **Changes in services or practices among or within local agencies.**

Four of the five pilot sites identified changes in local services or practices that supported children and families. These changes include the following:

- Approximately 50 percent of agencies in Island County adopted and implemented the Common Enrollment form.
- In Grant County, county staff began conducting regular meetings with local physicians to coordinate care. In addition, they addressed local service gaps by contracting with agencies in nearby counties to bring in needed services, such as a feeding team.
- Families identified as having a complex level of need in Whatcom County are referred to the local Lead Care Coordinator who convenes a team of all the local agencies that can meet the varied needs of the individual families.
- Children's Village identified and utilized more flexible sources of funding to support services needed by children and their families.
- Another change in practice among agencies identified by several of the pilot site representatives was an increased focus on addressing the needs of children with special health care needs and a willingness to be collaborative and creative about achieving goals for children and parents. In several cases, individuals at agencies have become more willing to think about how to meet the clients' needs rather than being driven by strict agency roles.
- Increased parent participation/engagement in the local process. All pilot sites experienced increased parent participation over the course of the WISE grant process. WISE grant support for parent leadership development, through resources and trainings, facilitated the development of meaningful local parent involvement. More parents have become involved in Steering Committee or subcommittee activities, and some parents have taken on new leadership roles. In several communities, as parents saw that they were valued and listened to, they became more inclined and empowered to become involved and assume leadership roles. While the lead agencies in the pilot communities already valued and included parents in their work, many shared that the WISE grant helped model ways to effectively engage parents as partners, not just as token participants.

*"Agencies are working together outside of their job boxes."* — Pilot site representative

Three of the five pilot sites identified changes in the attitudes toward and prioritization of integration among local agencies. As noted earlier, while most pilot communities already had a fairly high level of collaboration among agencies, this process helped recruit new partners and encouraged other partners to participate more fully. A key facilitator of this change was the state-supported focus on integration.



## Parent/Child Outcomes

While much of the grant focused on system-level outcomes, pilot communities that implemented goal area strategies (i.e., Grant County, Island County, Whatcom County and Yakima County) identified changes for the people they serve. Common outcomes identified by sites and parents include the following:

- Increased access to services for children with special health care needs.  
Access to services increased in three of the pilot site communities. This outcome occurred through agencies' efforts to have new services brought in (Grant County), fund new services (Yakima County), or better communicate about and coordinate among service providers (Whatcom County and Grant County). In the parent focus group, parents referred to the ability to have a "seamless opportunity for services" as agencies became more knowledgeable about what services were available from the local care system partners.
- Increased support for parents/decreased sense of isolation.  
Pilot site communities addressed parent support in several ways. In Grant County and Whatcom County, parents felt increased support through the strategy of care coordination. Parents in those communities now have a partner in the process of efficiently identifying and accessing needed services. Parents in Yakima County have increased support through the Parent to Parent Program that is supported by flexible funding.

## Observations and Lessons Learned from the Pilot Site Projects

Facilitators:

- Pilot communities started from a position of strength.
- Flexibility to meet local needs was an important component.
- State support validated the process.
- Having a framework for integration helped structure the process.
- Parent involvement was crucial.

Barriers/Lessons Learned:

- Laws and policies at state and federal levels hindered integration work.
- Goal areas currently have varying levels of practical implementation.
- Changes have primarily been informal and individual.

## Recommended Statewide System Changes Based on Pilot Site Experiences

Coordinators and parents from the pilot site communities have learned much about the process of integration over the past four years. Key facilitators and barriers observed include:

- Formalization of integration for services at the state level should be state-defined but community driven. Future state-level efforts to promote and extend local care

system integration should identify ways to support community-driven processes that define local needs.

- Parent involvement and leadership development of local parents must be supported so that parents are empowered to engage meaningfully in the process. Additional efforts should be made to increase diversity of parents.
- The State must adopt policies that complement the goals of systems integration. Federal and state level reporting, data systems, and privacy issues must be addressed for integration efforts to be formalized, efficient, and sustainable.

#### General Learnings:

- Don't lose the learning. The learnings from the pilot sites' experiences implementing integration goal area should be used to help guide other communities as they embark on their local processes.
- Don't start from scratch. Find existing groups that can support the process. Get the right people involved. Build in opportunities for reflection and sharing. Provide a framework for integration.

#### Common Application:

- Barriers in policy and law, including eligibility, entitlement, confidentiality, and federal law precedent, still need to be addressed.
- Pilot sites have valuable experience successfully addressing turf issues through increased communication and collaboration.

#### Care Coordination:

- Many of the policy and procedure barriers can be addressed through increased communication and collaboration across local agencies.
- Concerns regarding privacy must be considered.

#### Blended Funding:

- It is possible to find flexible funding to support efforts to meet local needs.
- Without more state-level support, comprehensive blended funding will not be an achievable goal.

## **D. Family Leadership Findings**

Input provided by Family Advisors and WFFN members during the four year grant period provided the following findings:

- Parent involvement and leadership development of local parents must be supported so that parents are empowered to engage meaningfully in the process.
- Additional efforts should be made to increase diversity of parents involved.

- The pains of integration-growth are mediated by family-professional partnerships and increased levels of leadership skill and mentoring.
- A statewide family leadership plan should incorporate WISE grant final recommendations into long range planning strategies that support integrated systems of care.
- A budget is needed to sustain current infrastructure of family leadership in Washington State.
- Greater emphasis is needed on developing cultural brokers who are parents of children with special needs, and who can assist families from diverse ethnic backgrounds navigate the system and apply for services.

## **E. Evaluation**

2002 short-term parent evaluation results included the following:

1. Parents validated three of the four goals:
  - Common enrollment/application process.
  - Care coordination.
  - Integrated data.
2. They expressed some skepticism about the fourth goal, (blended funding). However, they may find it acceptable if the following conditions were met:
  - If it made access for funds simpler.
  - If there were no cap.
  - If they did not have to understand how it worked.
3. The common enrollment process should be renamed common application process and be available in many formats in addition to the Internet. The process should include:
  - Formats to include phone, paper, and online.
  - Access to a support person to assist with the application process.

The benefits of a common application would be:

- Parents would not re-live the details so frequently.
  - The information would remain consistent and no details would be forgotten or overlooked.
4. Family resource coordinators in the Birth to Three Program are generally helpful for those who access care through the education services, especially children with developmental delay or autism.

- The medical home model suits parents whose children had serious medical needs, with doctor's staff seen as better able to perform care coordination than the physician.
  - The smart card was suggested as a record that would follow the child.
  - Some parents felt they were the only ones suited to coordinate care for the child, but most would prefer to have assistance.
5. Integrated data systems were seen as a positive step to the extent that the trend data would lead to better understanding of diseases or enhanced funding in the areas where need is greater.
- Parents could see the use of the data systems as greater than administrative as long as the different types and levels of access were layered.
  - They felt that this concept of integrated data overlapped well with the concepts of a common enrollment and care coordination.
  - It was perceived as the generator and back-up for the smart card information, if such a piece were implemented.
6. Integrated or blended funding was the most complicated concept and, thus, raised more concerns than perceived benefits. Parents indicated these as issues:
- Concern that it would not cap or funnel the funding away from their needs.
  - They would probably find blended funding acceptable if it was a seamless process.
7. Parents would like to see a greater emphasis on education. Respondents felt that one additional goal would be to inform the public about the issues and resources available and to educate the healthcare professionals so that they can provide better assistance in a more sensitive manner. Parents said:
- Initial resources are difficult to find, especially when parents are overwhelmed with the child's needs.
  - Greater awareness among the public (particularly among health care professionals) would make it easier to be directed to the primary contact point as soon as possible after diagnosis.
8. Most of the goals examined by the research were seen as dependent on one another. At the same time, respondents recognized that the circumstances and needs varied widely from family to family. Thus, a multi-modal system of coordination and integration was recommended.
9. The families represented in the group were very involved with the processes for care of their children with special health care needs and would like to continue to take leadership in development of child focused systems to facilitate their care.

## 2003 WISE Grant Member Evaluation Results included the following:

### Ways to improve future activities & outcomes:

#### Overall:

- Clarify expectations of members, expected outcomes and focus of grant.
- Develop clear timelines, gather another meeting of stakeholders where we review the timelines and objectives of the WISE Grant and look at our progress toward meeting them.
- Develop easy to read handouts including one that highlights pilot site accomplishments.
- Identify how to assist WISE Grant team in completing the administrative and coordination functions.
- Determine the questions we want answered with any information we collect.

#### Committee work:

- Utilize the Steering Committee to make decisions and take ownership of its goals and agenda.
- Provide action steps for meetings with a clear and detailed agenda sent two weeks prior to meetings, and organize meetings so that members understand focus.
- Have the WISE grant Steering Committee develop recommendations to blend funds.
- Integrate family involvement within the grant as a whole.
- Strategize how to strengthen leadership and buy-in at the state level for the pilot strategies and to overcome barriers.

Overall, twenty four members noted some type of change since beginning their work on the WISE Grant; four members noted no change; five did not provide feedback on this question.<sup>2</sup> A list of changes that have occurred, reported by WISE Grant members, is listed below:

- Involved in many data integration projects and looking at changes in our data system.
- I've learned a lot about local parent frustrations, hopes and the needs of families.
- I use the WISE Grant as a model, when my agency discusses integrated early care and education.
- Increased perspective on how much work is involved in developing change and planning recommendations for state government.
- As a pilot site, we have built upon our collaboration with our social service partners to the level in which they are willing to participate.

2. This change may not be due to a direct result of the WISE Grant, but to additional environmental influences.

- I have learned new information and met other parents and professionals who can be resources for our work.
- We have a better understanding of the fragmentation in groups that provide service to CSHCN.
- Several other data integration initiatives have started.
- Closer relationship with CSHCN Program Staff and MHLN.
- The No Wrong Door initiative is now called Coordinated Services Initiative.
- My networking system has increased and I have learned more of what other people are doing for CSHCN.
- As a parent, I have had the opportunity to see many different perspectives and my knowledge about all parts of system have expanded.
- Developed a better understanding of other programs and support systems.
- There is a great awareness throughout my agency about the goals of the WISE Grant and the problems facing families with children with special needs.
- Realization of the diversity of needs between counties.
- Increased understanding regarding need for evaluation.
- Increased sensitivity to needs of families and need for leadership training/ opportunities.
- Vision expanded of what we need to do to affect overall system change and the challenges involved.

## **V. Next Step Projects**

The following projects/activities emerged as a result of WISE Grant activities. These projects will continue to focus on service integration.

### **A. Wise Grant Action Step Meeting**

On July 28, 2005, the Department of Health Children with Special Health Care Needs Program hosted a WISE Grant Action Steps Meeting. The purpose of this meeting was to share and discuss WISE Grant Recommendations with stakeholders and launch next steps to further integrate systems for children and their families. The objective was to develop work plans and identify champions for each prioritized recommendation.

### **B. CONNECT (CSHCN Mock On-Line Application Project)**

Progress on the goal of common application moved forward in the last year of the grant by initiating work with the Department of Health Division of Information Resources Management for the development of a mock common application web based portal. The assessment, planning, and systems development that was accomplished with the WISE Grant, provided the foundation for this next step. A consultant was hired to:

- Design and provide a mock up of the proposed site.
- Provide recommendations for proposed implementation.
- Provide estimated costs for design, development, implementation, and maintenance.

The projected cost for site development and 5 years of ownership is \$1,629,083.00.

### **C. Collaboration – Healthy Mothers, Healthy Babies**

The Healthy Mothers, Healthy Babies, (HMHB), Coalition of Washington is a private non-profit organization whose mission is to serve as a catalyst for improvements in maternal, child, and family health. The Department of Health (DOH), contracts with this organization to operate a toll-free statewide information and referral hotline for access to information about health insurance, nutrition resources, family planning, child care, and immunizations. HMHB is proceeding with a plan to develop an on-line access project and has been working with the DOH and the WISE Grant to consolidate resources. Representatives from HMHB

have served on the WISE Steering Committee and other subcommittees, and WISE staff and parent representatives are serving on the HMHB On-line Access Project advisory council. Funds from the WISE Grant were contracted to HMHB in the spring of 2005 to assist them with their effort and to assure that the needs of children and families with special health care needs will be included in the project. The goal of the collaboration is to assure that HMHB develops a strategy for the integration of WISE Grant research and recommendations into their work, thus eliminating duplication of efforts

## **D. Family Leadership**

The CSHCN Family Consultant will continue to provide support and consultation to the Family Advisory Network parents who have participated in the WISE Grant and who sit on the Healthy Mothers, Healthy Babies On Line Access Project advisory board. Sustaining and increasing opportunities for family leadership will be a part of ongoing work for the CSHCN Program. This will include:

- The Title V Family Leadership Plan will continue to be developed as a statewide plan, incorporating the CSHCN national performance measures as well as the mission and values established by the Washington Family to Family Network, (WFFN) during year four of the WISE Grant. Actions will be taken to increase diversity, recruitment of new members, mentoring, parent-professional partnerships, leadership training, and implementation of WISE Grant family leadership recommendations. Development of the statewide family leadership plan will be accomplished in partnership with the Washington Family to Family Network.
- Family Advisory Network parents will be invited to continue their participation in policy and program development through participation in WFFN, future Champions for Progress efforts, family leadership institutes, advisory boards, and other opportunities. Two FAN members sit on the HMHB On-Line Access Project advisory board, which will provide continuity between WISE Grant efforts and the new work of the On Line Access Project.
- The Washington Family to Family Network (WFFN) was formerly an informal coalition of statewide family support organizations. The WISE Grant utilized WFFN as the key advisory board which supported WFFN to develop a formal mission and vision that supports the WISE Grant Recommendations. Their vision is to promote the value of quality statewide support system for children and youth with special needs and their families. WFFN will promote this by developing a network of diverse family leaders, coordinating a statewide system for sharing information and resources, working to increase stable funding for family support organizations, and engaging in other activities that support families.



## VI. Recommendations

### Service Integration

**Issue:** Families of children with special health care needs face a complex system of care. With multiple agencies providing a variety of services to children, families often find services difficult to locate, use and navigate.

**Recommendation 1.** Designate one lead entity to direct integration of services across agencies for children with special health care needs.

Recommended Actions:

- Coordinate with participating state agencies who have embarked on similar ventures to maximize integrations efforts.
- Reduce barriers to integration of services by reviewing and systematically changing RCW's and WAC's.

**Recommendation 2.** Involve parents and family leadership in all aspects of state program planning related to children with special health care needs.

Recommended Actions:

- Develop the capacity of providers and families to effectively use integrated systems of care through social marketing and user training.

### Common Application

**Issue:** Families often must complete numerous enrollment forms and provide information about their child repeatedly to various individuals in multiple agencies and programs. Families have often expressed dismay and frustration with this redundant, emotionally and physically exhausting process. Increasing the ease of enrollment would be beneficial to families and would reduce duplicative efforts in state systems.

**Recommendation 1.** Develop a system for a common application process for families and professionals to access local and state resources for children with special health care needs.

Recommended Actions:

- Participating state agencies agree to a common application process to make it easier for families to find information and enroll for services.
- Develop a web based portal to provide an avenue for families to learn about and apply for state and local services and resources. In addition to the web portal the following features should be considered:
  - Telephone access available
  - Paper copies available

- Culturally competent parent mentors and providers accessible to help navigate the web site
- Support resources and other information available regardless of income eligibility
- Information presented in many languages
- Social marketing campaign and broad visibility
- Neighborhood access through libraries, community service offices, etc.
- Create a task force with key representatives from each participating agency that will commit to linking key application data.
- Assure that all state agencies application processes, eligibility criteria, and child enrollment procedures are clear, documented in writing, and coordinated.
- Develop and implement a sustainable system to train participating agency staff to collect, analyze, and use application data. The training should include concepts related to application processes and eligibility criteria.

## Care Coordination

**Issue:** The system of care for children with special health care needs is complex, making it difficult for families to identify payment sources, locate family support, and access needed services. Families need a primary point of contact for care coordination that can most adequately meet the needs of the child and family.

**Recommendation 1.** Create a common care coordination vision and set of goals for agencies and families to use in providing care coordination for children with special health care needs.

Recommended Actions:

- Develop and implement a plan to promote complementary language in RCW and WAC related to Care Coordination in various systems in state agencies.
- Develop and disseminate a reference document that outlines roles of those who coordinate care.
- Coordinate and further develop existing web sites that provide information about care coordination.
- Develop training requirements with common language for all care coordinators/ case managers that includes knowledge about other agencies.

**Recommendation 2.** Promote the concept of a primary care coordinator to help facilitate services, across agencies, for children with special health care needs.

- Care coordinators will be chosen by families from an array of trained providers who understand the needs of the family and work together as a team.

## Blended Funding

**Issue:** Currently, a variety of state and federal resources for funding sources exists. Funding of services for children with special health care needs is complex, compounded by categorical funding streams, multi-agency responsibility for service provision, lack of health insurance, and difficulty in billing of services provided.

**Recommendation 1:** State agencies will combine funds whenever possible for activities, such as cross agency trainings, that will improve services for children with special health care needs.

**Recommendation 2:** Continue to research the benefits of blending funds for children with special health care needs across state agencies.

## Integrated Data

**Issue:** Many of the elements that can increase the integration of service for children with special health care needs, including common enrollment, continuity in care coordination, and even maximization of funding could be driven by integrated data systems. If appropriately designed, an integrated data system could meet the needs of all agencies that use it to promote the above mentioned integration enhancements and improve efficiencies in service delivery, resource allocation, and communication.

**Recommendation 1:** State agencies will commit to data integration for children with special health care needs as a long term goal.

**Recommendation 2:** State agencies will link data bases for children with special health care needs internally in order to establish quality improvement strategies and understand the needs of the population.

Recommended Actions:

- Develop a clear statement that specifies what data is to be collected and how it will be used.
- Develop an action plan for promoting the use of interagency data sharing agreements among departments and divisions of each relevant public agency.

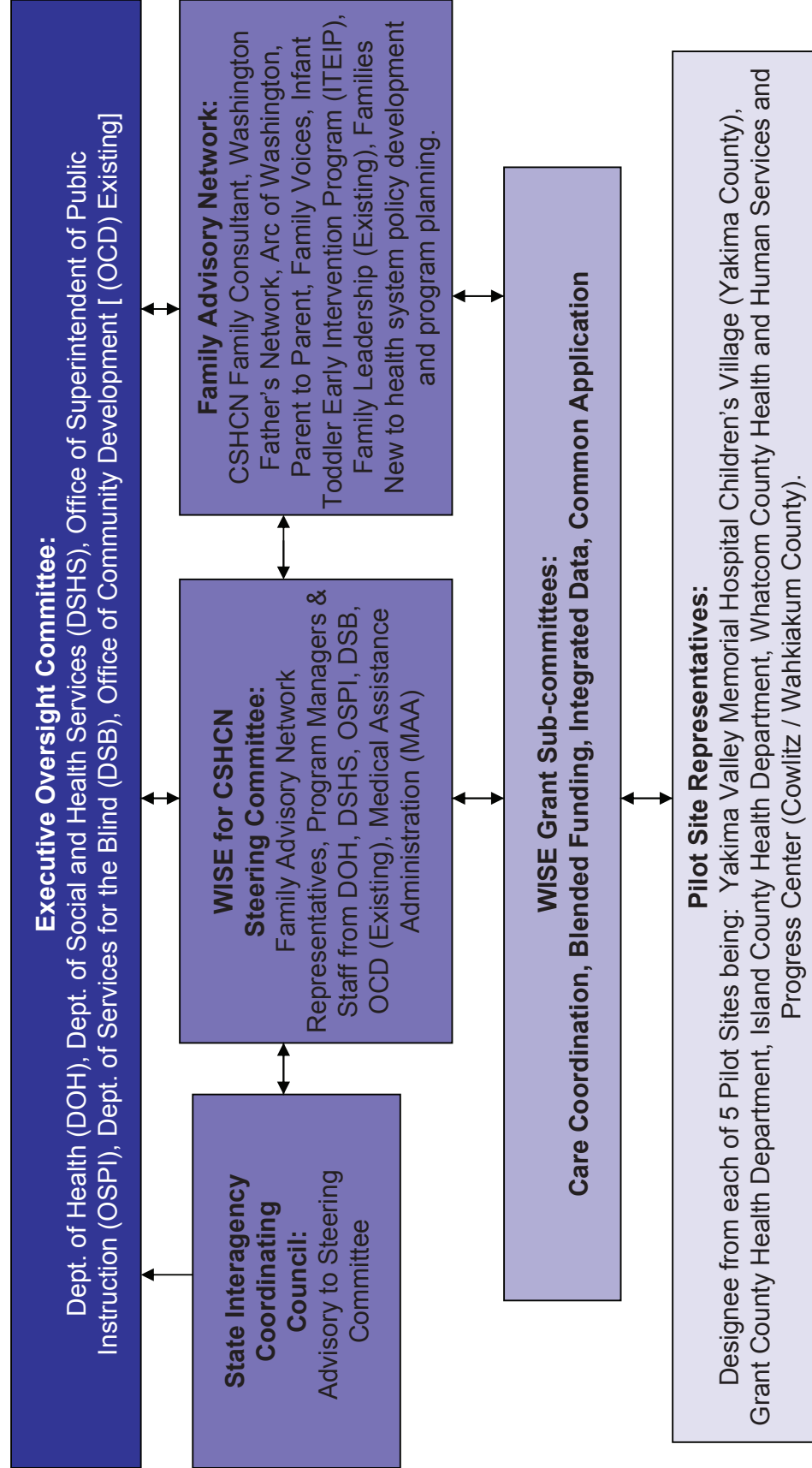


## Appendices

- A. WISE Organizational Chart
- B. Logic Model
- C. Systems Assessment Briefing Digest
- D. Pilot Site Evaluation Executive Summary
- E. Care Coordination Matrix



# Project Administrative Structure







## WISE Grant Logic Model, 2004

Input or Resources	Activities	Outputs	Short-Term Outcomes	Intermediate Outcomes	Long-Term Outcomes or Goals
<p>MCHBG</p> <p>DOH, CSHCN Program &amp; contractors</p> <p>Partnering state agencies (DSHS, OSPI, CTED)</p> <p>MCH Assessment</p> <p>Five Pilot Communities</p> <p>WFFN</p> <p>FAN</p> <p>Steering Committee and sub-committees</p> <p>Executive Leadership Committee</p>	<p>Coordinate WISE grant activities (meetings, adhoc, task forces)</p> <p>Gather and synthesize information about the system of service for children with special needs</p> <p>Develop and nurture relationships between WISE grant members</p> <p>Evaluate progress made toward achieving goals</p> <p>Provide technical assistance and consultation to pilot sites and learn what they learn</p>	<p>Focused state system assessment model</p> <p>WISE Grant Action Plan</p> <p>Proposed strategies for integration of services</p> <p>Number of parents trained in family leadership</p> <p>Briefing digest for state leadership on the roadmap for integration</p> <p>Annual Progress Reports</p> <p>Short and long term evaluation reports</p> <p>Number of WISE Grant Team meetings</p> <p>WISE Grant Website</p> <p>Family leadership Plan</p> <p>Number of committee meetings</p>	<p>Improve satisfaction of progress made toward four goals</p> <p>Increase number of local and state stakeholders involved in integration efforts</p> <p>Increase number of parents participating in family leadership activities</p> <p>Develop ongoing mechanism for communication of ways to improve integration of services</p> <p>Improve attitudes toward service integration</p> <p>Enhance level of perceived integration</p>	<p>Develop recommendations for service integration that will be validated by family leaders of Washington State</p> <p>Improve services for cshcn in Yakima County by blending funds</p> <p>Improve care coordination for cshcn in Grant, Whatcom and Island counties</p> <p>Improve application process to services for cshcn in Cowlitz County</p> <p>Increase capacity of state level data systems to develop a plan across agencies</p>	<p>Access, availability and continuity of services for children with special needs will improve</p> <p>Integration of services for children with special needs between state funded programs will improve</p>



## Integrating Washington State Public Services for Children with Special Needs



The purpose of this document is to provide a preliminary framework for public agency system integration for children with special needs. Models for integrating services must be specific and have clear action steps in order to know if they can be implemented.

### System Assessment Recommendations for Integration

#### A Model for Common Application

Families will learn about resources and complete a single application form when required for public services specific to children with special needs.

*"Service integration is growing in all state agencies."* —  
Key Informant Quote

1. Specify for which public services families may apply using a common application.
2. Develop a list of the core data elements and definitions required for common web-based application.
3. Assure that all state agencies' application processes, eligibility criteria, and child enrollment procedures are clear, documented in writing, and coordinated via contract, agreement or rule, with local sub-contractors and/or agencies.
4. Develop and implement a sustainable system to train agency staff to collect, analyze, and use application data. The training should include concepts related to application processes vs. eligibility criteria.

#### A Model for Data Integration

Data relevant to children with special needs from existing public agency databases will be linked.

*"HIPAA allows for data sharing as long as it is for business oversight, client monitoring and quality assurance."* —  
Key Informant Quote

1. Write a policy statement specifying what application and service data to collect and use.
2. Assure data collection procedures at each agency are clear, documented in writing, and coordinated via contracts or rules or agreements with local sub-contractors and/or agencies.
3. Promote the use of existing intra-agency data sharing agreements among departments and divisions of each relevant public agency.
4. Promote the use of inter-agency data sharing agreements and the Institutional Review Board process to share data about children with special health care needs among agencies.

#### A Model for Care Coordination

Families will have a single care coordinator to help facilitate and coordinate services for multiple public agencies.

*"Most agencies have policies to integrate and coordinate services."* —  
Key Informant Quote

1. Develop and implement a plan to promote complementary language in RCW and WAC related to care coordination in various systems in state agencies.
2. Develop and disseminate a reference document that outlines roles of those who coordinate care.
3. Assure that those who coordinate care are the bridge to resources for families.
4. Coordinate and further develop existing web sites that provide information about care coordination.
5. Develop a joint ongoing training system for those who coordinate care and families to assure each is aware of the roles, resources, and information available.

**Recommendation for Governance should be ensured by RCW and legislative oversight.**

### **Facilitators & Barriers to Integrating Public State Services for Children with Special Needs**

**Finding 1:** Models for integrating services must be specific and have clear action steps in order to know if they can be implemented.

**Finding 2:** Many programs must adhere to federal guidelines and laws that mandate service requirements.

**Finding 3:** There are formal processes that allow state law (RCW) and regulations (WAC) to be changed to achieve integration.

**Finding 4:** Each agency is challenged to assure sub-contractors, agencies or programs at local levels collect data and follow procedures in a uniform, consistent manner.

**Finding 5:** One agency or an interagency oversight committee must be designated to implement and direct integration of services for children with special needs.

### **Examples of Integrating Services for Children with Special Needs in Other States**

**Minnesota:** In 1998 the Minnesota state legislature passed a law requiring public agencies to coordinate care for children and youth with disabilities. [www.mnsic.org](http://www.mnsic.org)

**Nebraska:** Public agencies serving children, youth, and adults collaborated to create "CONNECT," an Internet based data collection and tracking system that enables clients to apply for multiple public services with one application. [http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-May-2003/Nebraska\\_2002.pdf](http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-May-2003/Nebraska_2002.pdf)

**Massachusetts:** The Massachusetts Consortium for CSHCN is a working group dedicated to improving systems of care for children with special health care needs and their families throughout the Commonwealth of Massachusetts. [http://www.neserve.org/maconsortium/mac\\_about.html](http://www.neserve.org/maconsortium/mac_about.html)

**Arizona:** *Building Community Health in Arizona:* At the community level, parent led Community Action Leadership Teams made up of public and private health care, education and social service agencies work to implement an integrated systems model. At the state system level, Departments of Health, Economic Security and Education implement laws and policies and disburse funding to provider organizations. <http://www.swifamilies.org/bchaz.htm>

**Utah:** The *Utah Universal Application System* is an Internet based application where families can apply for Utah programs and community resources such as Medicaid, Baby Watch Early Intervention, Head Start, and WIC. Personal information is protected by user name and password. <http://www.utahclicks.org/>

**Oregon:** *The Practice Based Community Connections Pilot Project* is a grant to Oregon Health Sciences University that explores innovative partnerships with a child's primary care practice site, managed care organization, parents, and state programs. <http://www.tgcgrantproposals.com/cgi-bin/fullResult.asp?purchNum=HHS-00-004>

#### **For more information contact:**

Washington Integrated Services Enhancement (WISE) Grant  
Washington State Department of Health  
Telephone: (360) 236-3546, (360) 236-3585  
[WISupport@doh.wa.gov](mailto:WISupport@doh.wa.gov)  
<http://www.doh.wa.gov/cfh/mch/WISE.htm>

## Washington Integrated Services Enhancement (WISE) Grant EVALUATION REPORT — EXECUTIVE SUMMARY



*Agencies are working to take the onus off of parents to seek out information and services for their children.*

— Parent

The Washington State Department of Health Children with Special Health Care Needs Program contracted with Organizational Research Services (ORS) in October 2004 to evaluate pilot site accomplishments of the Washington Integrated Services Enhancement (WISE) grant.

The evaluation synthesized the learnings of the pilot site projects through document review, interviews and focus groups, and incorporated findings from the state-level System Assessment Report to create a report that addresses the following:

- Pilot site successes, challenges, and outcomes;
- Overall outcomes achieved;
- Facilitators and barriers to successful service integration; and
- Recommendations for next steps to successfully integrate services for children with special health care needs and their families based on the experiences of pilot sites.

The findings detailed in the Evaluation Report contributed to state level findings and comprehensive system recommendations presented in *WISE Grant Final Recommendations for State Agencies*.

### GRANT BACKGROUND

Families of children with special health care needs face a complex system of care that is often difficult to navigate. The WISE grant is a federally-funded four-year grant (June 2001-August 2005) to improve care systems for children with special health care needs and their families.

Five communities piloted innovative strategies and solutions to promote integration across local care systems.

- **Common Application or Enrollment** (Cowlitz and Wahkiakum Counties, Island County): Families will learn about resources and complete a single application form when required for public services specific to children with special health care needs.
- **Care Coordination** (Grant County, Island County, Whatcom County): Families will have a single care coordinator to help facilitate and coordinate services from multiple agencies.
- **Blended Funding** (Yakima County): Funding from several sources will be “braided” to maximize service delivery to clients and eliminate duplication of resources.
- **Integrated Data** (not piloted): A WISE grant data task force focused on developing strategies to link data sets rather than designing a data warehouse.

In addition to piloting integration strategies, the grant aimed to develop parent leadership to support family involvement in local processes.

### CROSS-SITE OUTCOMES

The WISE grant changed the way that agencies and systems work with clients and each other, leading to outcomes at the agency/system level and for parents and children.

#### Agency/System Outcomes:

- Increased collaboration among local agencies and organizations.
- Increased communication across agencies.
- Increased efficiency of local care systems.
- Increased integration of local care systems.
- Changes in services or practices among or within local agencies.
- Increased parent participation in the local process.
- Increased positive attitudes toward and prioritization of integration.

#### Parent/Child Outcomes:

- Increased access to services for children with special health care needs.
- Increased support for parents/decreased sense of isolation.
- Increased feelings of empowerment/leadership skills for parents.
- Increased parent satisfaction.



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## OBSERVATIONS AND LESSONS LEARNED

Coordinators and parents from the pilot site communities have learned much about the process of integration over the past four years. Their observations were synthesized into the following list of key facilitators and barriers.

### Facilitators:

- Pilot communities started from a position of strength.
- Flexibility to meet local needs was an important component.
- State support validated the process.
- Having a framework for integration helped structure the process.
- Parent involvement was crucial.

### Barriers/Lessons Learned:

- Laws and policies at state and federal levels hindered integration work.
- Goal areas currently have varying levels of practical implementation.
- Changes have been primarily informal and individual.

*When a parent is coping with the medical needs of a child, the weight of clumsy systems and the barriers of getting support that isn't as strong as it could be becomes a real obstacle for families meeting their goals.*

— Pilot site representative

For further information on evaluation methods and data, contact: Sarah Stachowiak, MPA or Hallie Goetz, MPA, Organizational Research Services, Seattle, WA, 206.728.0474, [www.orgizationalresearch.com](http://www.orgizationalresearch.com)

## EVALUATION REPORT RECOMMENDATIONS

A major goal of the WISE grant and this evaluation was to develop recommendations for statewide systems change based on the experiences of the pilot communities.

1. Formalization of integration for services at the state level should be state-defined but community-driven.  
Future state-level efforts to promote and extend local care system integration should identify ways to support community-driven processes that define local needs.
2. Parent leadership must be supported.  
Parent involvement and leadership development of local parents must be supported so that parents are empowered to engage meaningfully in the process. Additional efforts should also be made to increase the diversity of parents involved and providing input.
3. The state must adopt policies that complement the goals of systems integration.  
Federal- and state-level reporting, data systems and privacy issues must be addressed for integration efforts to be formalized, efficient and sustainable.
4. Don't lose the learning.  
The learnings from pilot sites' experiences implementing integration goal areas should be used to help guide other communities as they embark on their local processes.

### General Learnings

- Don't start from scratch. See if existing groups can support the process.
- Get the right people involved.
- Build in opportunities for reflection and sharing.
- Provide a framework for integration.

### Common Application

- Barriers in policy and law, including eligibility, entitlement, confidentiality, and federal law precedence, still need to be addressed.
- Pilot sites have valuable experience successfully addressing turf issues through increased communication and collaboration.

### Care Coordination

- Many of the policy and procedure barriers can be addressed through increased communication and collaboration across local agencies.
- Concerns regarding privacy must be considered.

### Blended Funding

- It is possible to find flexible funding to support efforts to meet local needs.
- Without more state-level support, comprehensive blended funding will not be an achievable goal.

5. Always remember the children and their families.  
Pilot sites repeatedly talked about the need to maintain focus on children with special health care needs and their families. By keeping family stories as a touchstone, pilot site communities stayed on track and harnessed energy for the process.

The findings presented in the Evaluation Report contributed to state level findings and comprehensive system recommendations presented in *WISE Grant Final Recommendations for State Agencies*. For further information on the WISE grant, contact: Children with Special Health Care Needs (CSHCN) Program, Olympia, WA, 360.236.3571, [cschn.support@doh.wa.gov](mailto:cschn.support@doh.wa.gov).

## Guide to Care Coordinators in Washington State

Care Coordinators or Case Managers<sup>1</sup> are professionals working in Washington State public agencies whose job it is to coordinate and connect supports, services and resources for children with special needs and their parents at home, in child care, in school, and in health care and other community settings. The Association of Maternal Child Health Programs identifies at least four types of care coordination families need<sup>2</sup>:

- **Family-Centered Care Coordination**-focuses on family needs and family satisfaction by providing an individual services plan for the family, negotiating for families, providing appropriate training and information for families, and monitoring family needs across time.
- **Administrative Case Management**-provides referral to services, eligibility determination and claims processing in an attempt to ensure a smoother administration of services and protect against undue costs.
- **Systems Improvement Model**-focuses on integrating services for families and the community to ensure that gaps in the service system are filled, that families are connected with community services, and that families don't have to repeat evaluations or treatments unnecessarily.
- **Financial Case Management**-attempts to redesign service systems to reduce costs to systems and families.

This guide includes information about:

- **Job Requirements for Care Coordinators Working in Public Agencies**
- **Agency Definition of Care Coordination and Client Eligibility**
- **Services Provided**

<sup>1</sup> Only people who work for public agencies, and whose primary job it is to coordinate care for children with special needs, are included in this information.

<sup>2</sup> Association of Maternal Child Health Programs, "Meeting the Needs of Families: Critical Elements of Comprehensive Care Coordination in Title V Children with Special Health Care Needs Programs", January, 2002, [www.amchp.org](http://www.amchp.org)

Guide to Care Coordinators in Washington State

Family Resource Coordinator (FRC)

Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Infant Toddler Early Intervention Program, Division of Developmental Disabilities, Washington State Department of Social and Health Services</p> <p>FRCs are located in early intervention settings such as Neurodevelopmental or Developmental Disability Centers throughout the state.</p> <p><b>Education requirement:</b> Varies based upon hiring agency. FRCs must have three days of basic training soon after hire and twelve contact hours yearly thereafter.</p>	<p><b>Definition:</b> The activities carried out by an FRC to assist and enable a child eligible under Part C, and the child's family, to receive the rights, procedural safeguards, and services that are authorized to be provided under Washington State's early intervention program (303.6).</p> <p><b>Client eligibility for Part C IDEA services:</b> Children from birth up to three years of age who have a delay of 1.5 standard deviations or 25% upon assessment, in: cognitive, physical, communication, social-emotional or adaptive functioning, or a child with a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay.</p>	<p>The FRC provides service coordination activities. She/he has demonstrated knowledge and understanding about infants and toddlers eligible under IDEA, Part C and the regulations in Part C 34, CFR Part 303, the nature and scope of services available under Washington State's early intervention program, the system of payment for services in Washington State programs, and other pertinent information (303.6).</p> <p><b>The FRC is responsible for:</b></p> <ul style="list-style-type: none"> <li>• Coordinating all services across agency lines.</li> <li>• Serving as a single point of contact in helping parents to obtain the services and assistance they need.</li> <li>• Assisting parents in gaining access to early intervention services and other services identified in the Individual Family Service Plan (IFSP).</li> <li>• Coordinating the provision of early intervention services and other services that the child needs or receives.</li> <li>• Facilitating the timely delivery of available services, and continuously seeking appropriate services and situations necessary to benefit the development of each child served for the duration of the child's eligibility.</li> </ul> <p>To learn more visit <a href="http://www1.dshs.wa.gov/geninfo/infants.html">http://www1.dshs.wa.gov/geninfo/infants.html</a></p> <p><b>Source:</b> Infant Toddler Early Intervention Program, Division of Developmental Disabilities, Washington State Department of Social and Health Services</p>





## Guide to Care Coordinators in Washington State

### Developmental Disabilities Case Resource Manager

Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Division of Developmental Disabilities (DDD), Aging and Disabilities Services Administration, Washington State Department of Social and Health Services (DSHS)</p> <p>DDD Case Resource Managers are located in Regional Offices in each of the six DSHS Regions and outstations in the Regions.</p> <p><b>Education requirement:</b> Bachelor's degree in a social services field.</p>	<p><b>Client eligibility:</b> Any individual who has a developmental disability that starts before age 18 years, results in a substantial handicap, and is expected to continue indefinitely, may be eligible for DDD services.</p> <p><b>Developmental disabilities are:</b></p> <ul style="list-style-type: none"> <li>• Mental retardation</li> <li>• Developmental delay (ages birth to six years)</li> <li>• Cerebral palsy</li> <li>• Epilepsy</li> <li>• Autism</li> <li>• Other neurological conditions or conditions similar to mental retardation.</li> </ul>	<p>DDD Case Resource Managers determine eligibility for services, identify needs, and develop, monitor, and coordinate service plans. This person also authorizes payments for division services and other services available through the Aging and Disabilities Services Administration.</p> <p><b>The DDD Case Resource Manager is responsible for:</b></p> <ul style="list-style-type: none"> <li>• Determining eligibility for DDD services.</li> <li>• Needs assessments.</li> <li>• Plan of Care for people with DDD waivers.</li> <li>• CARE Assessment for people receiving Medicaid Personal Care.</li> <li>• By 2006 a Mini Assessment will be completed on people eligible for DDD but receiving no paid service.</li> <li>• By 2007, a full assessment will be completed on all people receiving a DDD service.</li> <li>• Service authorization via Social Services Payment System.</li> <li>• Monitoring and coordination of authorized services.</li> <li>• Providing resource information and referral services for clients birth through adulthood.</li> <li>• County Interagency Coordinating Council efforts.</li> </ul> <p>To learn more visit  <a href="http://www1.dshs.wa.gov/ddd/index.shtml">http://www1.dshs.wa.gov/ddd/index.shtml</a></p> <p>Source: Division of Developmental Disabilities, Washington State Department of Social and Health Services</p>

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Children with Special Health Care Needs Program

Guide to Care Coordinators in Washington State

Children with Special Health Care Needs (CSHCN) Coordinator

Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Children with Special Health Care Needs (CSHCN) Program, Washington State Department of Health</p> <p>CSHCN Coordinators are public health nurses located in the thirty-four local health departments throughout the state.</p> <p><b>Education requirement:</b> Bachelor of Science degree in nursing with specialization in public health nursing, or graduation from a state-accredited school of nursing supplemented by public health training. Current Washington State registered nursing license.</p>	<p><b>Definition:</b> Care coordination promotes the effective and efficient organization and utilization of services for children with special health care needs and their families.</p> <p>Care coordination is a process for:</p> <ul style="list-style-type: none"> <li>Identifying a child's health or developmental needs, family strengths, concerns, priorities, and resources.</li> <li>Assisting families to find and establish services they want and need.</li> <li>Facilitating on-going identification of needs and coordination of resources.</li> </ul> <p><b>Client Eligibility:</b> Children age birth to 18 years who have or are at risk of having a serious physical, developmental, behavioral or emotional condition; who require health and related services of a type and amount beyond what is generally required, and who reside in Washington State.</p>	<p><b>The CSHCN Coordinator is responsible for:</b></p> <ul style="list-style-type: none"> <li>Helping families access needed services for their child such as medical care and other intervention.</li> <li>Referring families to health insurance programs and information, both private insurance and the state funded Medicaid Program.</li> <li>Helping families help each other through parent support organizations.</li> <li>Helping with concerns such as feeding nutrition, growth, development and behavior.</li> <li>Providing screening and assessment.</li> </ul> <p>To learn more visit <a href="http://www.doh.wa.gov/cfh/mch/cshcnhome2.htm">www.doh.wa.gov/cfh/mch/cshcnhome2.htm</a></p> <p><b>Source:</b> Case Management/ Service Coordination Matrix prepared by the WISE grant Care Coordination Committee, 2002 and Children with Special Health Care Needs Program brochure, Washington State Department of Health Publication #970-108</p>



## Guide to Care Coordinators in Washington State

## Mental Health Provider

Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Mental Health Division, Washington State Department of Social and Health Services</p> <p>Mental Health Providers are located in community mental health agencies that are part of the Regional Support Networks (RSN). RSNs are county-based administrators of the public mental health system.</p> <p><b>Education requirements:</b> Per WAC 388-865-0405: The licensed service provider must ensure that staff are qualified for the position they hold and have the education, experience, or skills to perform the job requirements. All staff must have a current Washington State DOH license or certificate of registration as may be required for their position. Staff must undergo Washington State Patrol background checks. Mental health services are provided by a mental health professional (MHP), or under the clinical supervision of a MHP.</p>	<p><b>Definition:</b> The community support service provider for case management services must assure that all general minimum standards for community support services are met (per WAC 388-865-0400 to -0456).</p> <p><b>Client eligibility:</b> Medicaid eligible children/youth who, through an intake assessment, demonstrate medical necessity and meet the Access to Care Standards, are authorized to receive outpatient mental health services in accordance with the Regional Support Networks Level of Care Guidelines.</p>	<p>Mental Health Rehabilitation services are integrated treatment services recommended by a mental health professional and provided by state licensed Community Mental Health Agencies. Services are provided to seriously mentally ill adults and seriously emotionally disturbed children for whom the services are determined to be medically necessary. These services must be provided to reach the goals of an Individualized Service Plan.</p> <p><b>Services include:</b></p> <ul style="list-style-type: none"> <li>• Brief intervention or treatment</li> <li>• Crisis services</li> <li>• Day support</li> <li>• Family treatment</li> <li>• Freestanding evaluation and treatment</li> <li>• Group treatment services</li> <li>• High intensity treatment</li> <li>• Individual treatment services</li> <li>• Intake evaluation</li> <li>• Medication management</li> <li>• Medication monitoring</li> <li>• Mental health services provided in residential settings</li> <li>• Peer support</li> <li>• Psychological assessment</li> <li>• Rehabilitation case management</li> <li>• Special population evaluation</li> <li>• Stabilization services</li> <li>• Therapeutic psycho-education</li> </ul> <p>To learn more visit <a href="http://www1.dshs.wa.gov/mentalhealth">www1.dshs.wa.gov/mentalhealth</a></p> <p>Source: Mental Health Division, Washington State Department of Social and Health Services</p>

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Guide to Care Coordinators in Washington State

School Nurse Job Requirements for Care Coordinators Working in Public Agencies	Agency Definition of Care Coordination and Client Eligibility	Services Provided
<p><b>Agency:</b> Washington State Office of Superintendent of Public Instruction</p> <p><b>Education requirements:</b> School nurses in Class I districts must hold an Educational Staff Associated (ESA) certificate.</p>	<p><b>Definition:</b> The school nurse provides case management for students in her/his caseload and interacts with parents, primary health care providers, community, and school resources to provide a school environment that is safe, healthy, and conducive to learning. These services vary depending upon availability of nursing services.</p> <p><b>Client eligibility:</b> All students in public schools are eligible for school nurse services. Contact a school nurse for client referral.</p> <p><b>Source:</b> Washington State Nursing Quality Assurance Commission, Washington State Office of Superintendent of Public Instruction, April, 2000</p>	<p>Case management of children with special health care needs involves activities designed to ensure the health and educational success of the child at school. It is the position of the National Association of School Nurses that school nurses have knowledge, experience and authority to be the case manager for children with special health care needs. This includes, but is not limited to:</p> <ul style="list-style-type: none"> <li>• Knowledge about services needed by students with special health care needs, after collaboration with student, family and health care provider.</li> <li>• Knowledge about community services and assisting families in obtaining needed services.</li> <li>• Screening for students who would qualify and benefit from case management services for their health care needs.</li> <li>• Providing leadership in interdisciplinary team meetings to assist in planning needed services to meet the health and educational needs of the students.</li> <li>• Implementing the health team's care plan by providing direct or indirect care.</li> <li>• Coordinating continuity of care between home and the school.</li> <li>• Monitoring and evaluating interventions and implementation of the health care plan.</li> <li>• Monitoring and evaluating progress toward health and educational goals.</li> <li>• Training, monitoring, and evaluating personnel delegated to perform specific nursing care.</li> </ul> <p>A case management team is essential in ensuring care is provided in a coordinated and effective manner for students with special health care needs. The school nurse must assume the leadership position as case manager in this process. The school nurse, in the role of case manager, provides oversight of care and services and serves as the point of contact for communication among the student, family, school staff, and health care provider.</p> <p>To learn more visit <a href="http://www.k12.wa.us/HealthServices/default.aspx">http://www.k12.wa.us/HealthServices/default.aspx</a></p> <p><b>Source:</b> National Association of School Nurses Position Statement, "Case Management of Children with Special Health Care Needs", adopted June 1995; revised: October 2002.</p>

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